

Agency and Decision-making with Advocacy Support: a qualitative study of people with dementia living alone

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Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

Ethics approval was granted by the Tasmanian Social Science Human Research Ethics Committee on the 02/04/11, reference no H0011667.

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Abstract

This thesis explores the power of people with dementia who live alone to participate in decision-making processes with advocacy support. Although the benefits of consumer participation in healthcare decisions include improvements in health outcomes, greater emotional well-being and long-term cost savings, people with dementia who live alone are frequently marginalised in the decision-making process. This is significant given that this group is increasing in number and is over-represented in statistics on early admission to institutional care. This study specifically examined how dementia affected the agency of people living alone, and how a dementia advocacy service influenced their participation in decision-making.

The study employed multiple methods to collect qualitative data from nine people with dementia living alone who have used advocacy services, four dementia advocates and twenty-one healthcare professionals involved in meeting care-assessment needs and in referring clients to the advocacy service. A critical realist theoretical framework and a process of retroduction were used to develop an explanatory theory.

This study found that dementia significantly constrained agency and led to a narrowing of the social world of participants with dementia. Orientations of agency towards the present and future improved power of agency as did a person's belief in their ability to take action, and advocacy was shown to positively influence these factors. Participation in decision-making was found to be extremely important to participants with dementia but sociocultural factors restricted their participation. Lack

of understanding of the variation in decision-making capacity associated with dementia and a strong cultural focus on risk avoidance resulted in low prioritisation of decision-making involvement by healthcare professionals. In contrast, advocacy facilitated participation through trusting relationships, spending time to understand the person's wishes and promoting the rights of the person with dementia living alone.

These findings suggest the need for healthcare services to focus on enhancing agency, to encourage supportive decision-making, and to balance safety and emotional consequences of decisions when working with people with dementia living alone.

Further, although advocacy provided benefits in protecting and facilitating participation, future success is contingent upon the establishment of a common understanding of advocacy and the advocate role and a universal approach to capacity and risk assessments.

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List of Acronyms

ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ATI	Advocacy Tasmania Inc.
CFC	Consumer Focus Collaboration
CHF	Consumer Health Forum
GDS	Global Deterioration Scale
IMCA	Independent Mental Capacity Advocate
MCI	Mild Cognitive Impairment
NACAP	National Aged Care Advocacy Program
NDAP	National Disability Advocacy Program
NHPA	National Health Priority Area
NDAP	National Disability Advocacy Program
QOL	Quality of Life
QOL-AD	Quality of Life assessment tool
SDAC	Survey of Disability, Ageing and Carers
UBACC	University of California Brief Assessment of Capacity to Consent
WDLA	with dementia living alone
WHO	World Health Organisation

Chapter 1: Introduction

Introduction

During the 21st century, consumer participation has become a significant element of many healthcare legislative systems worldwide (Pathways through Participation 2009; Thompson 2007). The reason for this phenomenon is a growing recognition that participation not only increases quality of life and treatment effectiveness for patients, but also can deliver service improvements and long-term cost savings (Church et al. 2002; Elwyn et al. 2000; Thompson 2007). Although the requirement for consumer participation is now reflected in most healthcare policies, people with dementia – particularly those who live alone – have been reported to be one of the most marginalised and disenfranchised groups in society (Clare & Cox 2003; Mapes 2009; Webber, Fox & Burnette 1994). In recent years, advocacy services have been working to give voice to people with dementia living alone (WDLA) (Goldsmith 1996; Mapes 2009). In spite of this, a review of the literature undertaken for this study has shown that no specific studies have been conducted on consumer participation of people WDLA. Additionally, although many descriptive examples and various claims on the effectiveness of dementia advocacy were found, few critical studies were identified (Dunning 2005; Manthorpe & Martineau 2010; Scourfield 2007; Townsley, Marriott & Ward 2009).

The aim of this research is to explore the power of people WDLA to participate in decision-making processes with advocacy support. Participation is dependent upon a person's agency, which is their ability to take action (Campbell 2009). Therefore, this study examined how dementia affects agency and the interdependent relationship between the exercise of agency and social structures. The study also explored the ways in which

advocacy, as a social structure, may facilitate participation of people WDLA in the decision-making process. Data for the study were gathered via in-depth interviews with advocates from a dementia advocacy organisation based in Tasmania, Australia, and with clients of the advocacy service, or, more precisely, people WDLA. The perspectives of healthcare professionals on their experiences of the dementia advocacy service were also collected through focus groups or individual interviews.

This thesis reports on the impact of dementia on agency and identifies the factors influencing agentic action of people WDLA. In addition, the thesis identifies the features of advocacy that facilitate participation of people WDLA. The thesis concludes with a summary of the issues and considerations for future participation of people WDLA and involvement of the dementia advocacy service.

People WDLA in Australia

Dementia is not a single specific disease, it is an umbrella term used to describe a syndrome associated with more than 100 different diseases (Australian Institute of Health & Welfare 2012). The Australian Institute of Health and Welfare characterises dementia as:

‘the impairment of brain functions, including language, memory, perception, personality and cognitive skills. Although, the type and severity of symptoms and their pattern of development varies with the type of dementia, it is usually of gradual onset, progressive in nature and irreversible.’ (Australian Institute of Health & Welfare 2012, p. 2)

There are many different forms of dementia, with the four most common types being Alzheimer’s disease (accounting for 50% to 70% of cases), vascular dementia (accounting for around 20% to 30% of cases), frontotemporal dementia, which includes Pick’s disease (accounting for 5% to 10% of cases) and Lewy Bodies disease (accounting

for 5% of cases) (Australian Institute of Health & Welfare 2012). Individuals may also develop dementia in relation to other less common conditions such as Parkinson's disease, Huntington's disease, Down syndrome, HIV/AIDS and alcohol-related conditions (Australian Health Minister's Conference 2006).

On 10th August, 2012, the Australian Health Ministers recognised dementia as the ninth National Health Priority Area (NHPA) (Australian Institute of Health & Welfare 2012). Currently, it is the leading single cause of disability in older people and is also one of the fastest growing sources of major disease burden (Access Economics 2009). Although dementia is not a natural part of ageing, the likelihood of being diagnosed with dementia doubles every five years after the age of 65, and there is a one in four chance of people over the age of 85 years old developing dementia (Access Economics 2005). In Australia, women on average tend to live approximately five years longer than men and, as a result, women have a higher prevalence of dementia (Australian Health Minister's Conference 2006). The prevalence of dementia in Australia is forecast to increase from approximately 298,000 people in 2011 to just over 981,000 people in 2050 (Australian Institute of Health & Welfare 2012). Dementia also occurs in younger people; when the condition is diagnosed in a person under 65 years old, it is classified as 'younger onset dementia' (Australian Institute of Health & Welfare 2012). In Australia, it is estimated that 9,600 people have younger onset dementia, which is predicted to rise to 14,220 by 2020 (Access Economics 2005).

In addition to the increased number of people with dementia, there is also a growing trend of people living on their own (Ebly, Hogan & Rockwood 1999; Gilmour 2004; Webber, Fox & Burnette 1994). However, the exact size of the population WDLA is unknown as there is currently no reliable method to measure it (Newhouse et al. 2001). In 2009, a national Australian Survey of Disability, Ageing and Carers (SDAC) was conducted to

collect information about three population groups: people with a disability, older people, and carers (Australian Institute of Health & Welfare 2012). This survey found that approximately 12 per cent of people with dementia were living alone in a private dwelling (Australian Institute of Health & Welfare 2012). The actual percentage of people WDLA is thought to be considerably higher as these results were self-reported and it is acknowledged that people WDLA are less likely to recognise their own cognitive impairment (Australian Institute of Health & Welfare 2012; Lehmann et al. 2010). Therefore, data sources which rely on respondents to report the existence of specific conditions are less reliable for determining the prevalence of dementia (Australian Institute of Health & Welfare 2012).

In Australia, assessment of care needs is an integral step for people seeking access to Australian Government-subsidised aged care services (Australian Institute of Health & Welfare 2012). Such assessments are conducted by Aged Care Assessment Teams (ACATs) which operate under the Aged Care Assessment Program (ACAP) (Australian Institute of Health & Welfare 2012). During 2008-2009, at the time of assessment 85 per cent of ACAP clients with dementia were living in the community; of these clients, 62 per cent (25,739 persons) were living with family and 34 per cent (13,855 persons) were living alone (Australian Institute of Health & Welfare 2012). This figure may be a more accurate reflection of the number of people WDLA in Australia as it is also consistent with other studies in the literature which report that approximately one third of community-dwellers with dementia live alone (Ebly, Hogan & Rockwood 1999; Nourhashemi et al. 2005; Prescop et al. 1999; Sibley et al. 2002; Webber, Fox & Burnette 1994).

Characteristics of people WDLA

People WDLA can be classified as: those who live alone but have local family caregivers, those who have long-distance family caregivers, and those who have no family members to provide care (Newhouse et al. 2001; Soniat & Pollack 1993). Only a small number of studies have been conducted on these groups as, until recently, it was incorrectly assumed that few people with dementia live alone (Webber, Fox & Burnette 1994). Many of the studies which have been conducted with people WDLA are epidemiological studies comparing the demographics, characteristics and service utilisation of people WDLA to those with dementia residing with others (Ebly, Hogan & Rockwood 1999; Edwards & Morris 2007; Tuokko, MacCourt & Heath 1999; Webber, Fox & Burnette 1994). Although these studies contribute to knowledge of the characteristics and service utilisation patterns of people WDLA there are some limitations. Most studies are quite dated, reporting from the mid to late 1990s, and the majority of these studies were conducted in the United States and Canada (Gould et al. 2010). In addition, in all studies participants were aged 65 years and over, and no information on the demographics or service utilisation of those with younger onset dementia who are living alone is provided. Table 1, below, provides a summary of characteristics of people WDLA compared to those co-residing:

Table 1: Comparison of the characteristics of people WDLA to those co-residing

	People WDLA compared to those co-residing are:
Characteristics	More likely to be older, poorer and female (Ebly, Hogan & Rockwood 1999; Edwards & Morris 2007; Miranda-Castillo, Woods & Orrell 2010; Nourhashemi et al. 2005; Prescop et al. 1999; Sibley et al. 2002; Tuokko, MacCourt & Heath 1999; Webber, Fox & Burnette 1994).
Level of impairment	More likely to be less cognitively and functionally impaired (Edwards & Morris 2007; Lehmann et al. 2010; Miranda-Castillo, Woods & Orrell 2010; Prescop et al. 1999; Webber, Fox & Burnette 1994).
Service usage	More likely to use community support services such as home-delivered meals, homemaker chores and case management and less likely to use adult day care centres, respite and medical or hospital services (Ebly, Hogan & Rockwood 1999; Edwards & Morris 2007; Miranda-Castillo, Woods & Orrell 2010; Tuokko, MacCourt & Heath 1999; Webber, Fox & Burnette 1994).
Institutionalisation	Significantly more likely to be admitted to institutional care earlier (O'Connor, DW et al. 1991; Waugh, F 2009).
Carers	More likely to have less local family support but greater involvement of neighbours and friends (Edwards & Morris 2007). Of those who have family carers, children are found to be the predominant carers and are more likely to be younger than carers who co-reside (Ebly, Hogan & Rockwood 1999; Tuokko, MacCourt & Heath 1999). Thirty per cent of people WDLA have no identified informal carer (Webber, Fox & Burnette 1994). Carers of people WDLA are significantly less likely to be depressed and experience lower levels of burden (Ebly, Hogan & Rockwood 1999; Miranda-Castillo, Woods & Orrell 2010).

These studies suggest people WDLA use healthcare services less frequently than those living with others (Ebly, Hogan & Rockwood 1999; Edwards & Morris 2007; Miranda-Castillo, Woods & Orrell 2010; Tuokko, MacCourt & Heath 1999; Webber, Fox & Burnette 1994). In fact, Webber, Fox and Burnette (1994) found that living alone with dementia was often a major predictor of no service use. Consistent with these findings, in a study of 343 African Americans with dementia, 61 per cent of those who lived alone were rated by social workers as receiving inadequate support and supervision in comparison to 25 per cent of those who lived with others (Edwards & Morris 2007). This low level of service use means that people WDLA often only become known to healthcare services following a crisis, which then frequently leads to institutionalisation (Waugh, F 2009). In addition decisions to institutionalise people WDLA are usually made by healthcare professionals without input from people WDLA (Boyle 2008).

The need to identify the barriers to accessing care and to facilitate the participation of people WDLA in the decision-making process was identified in the National Framework for Action on Dementia 2006-2010 (Australian Health Minister's Conference 2006). This Framework, however, provides little information on how these needs for access and participation are to be met for people WDLA. Further, the epidemiological studies which have been conducted have limited capacity to explore the reasons why people WDLA do not engage with healthcare services.

Consumer Participation in Health

Consumer participation in health is commonly seen as an ethical and democratic right and a way of providing legitimacy to decision-making (Cornwall 2008; Gregory 2007). The World Health Organisation (WHO) defines participation as a central element in its International Classification of Functioning, Disability and Health (World Health Organisation (WHO)). In spite of this, there is no clear definition of participation, nor

consensus on the associated terminology (Bathgate & Romios 2011; Church et al. 2002; Gregory 2007). Different terms such as ‘consumer’, ‘citizen’, ‘community’, ‘public’, ‘patient’, in association with ‘participation’, ‘involvement’ and ‘engagement’ are frequently found in the literature (Church et al. 2002; Gregory 2008). For the purpose of this study the terms ‘consumer’ and ‘participation’ are used.

Lack of consensus has led to different interpretations among healthcare professionals, and their approaches to participation often reflect their particular interests and motivations (Church et al. 2002; Feingold 1977; Rifkin 1996). Church et al. (2002) found that there are generally two distinct participation models: the biomedical model and the community development model. The biomedical model is directed by the healthcare professional and is concerned with initiatives aimed at improving a person’s illness or environment (Church et al. 2002). Clare and Cox (2003) believed that this model was rooted in patriarchal power structures which assume that the healthcare professional knows best.

In contrast, the community development model is much broader and sees participation as a means of improving the wider determinants of health and ensuring the inclusion of all citizens (Church et al. 2002; Clare & Cox 2003). Various attempts to establish a framework outlining the possible levels of consumer participation have been developed (Arnstein 1969; Charles & DeMaio 1993; Feingold 1977). One of the most influential authors is Sherry Arnstein who claimed that:

Citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be included in the future.
(Arnstein 1969, p. 216)

In 1969, Arnstein was the first to develop a ladder of participation (see Figure 1), consisting of eight rungs, where each rung corresponds to the extent of consumer

involvement (Arnstein 1969). The bottom rungs describe levels of non-participation, the middle rungs identify levels of ‘tokenism’ where the consumer may voice an opinion but no assurance is provided that these views will be considered during the decision, while at the highest rungs decisional control lies with the consumer (Arnstein 1969).

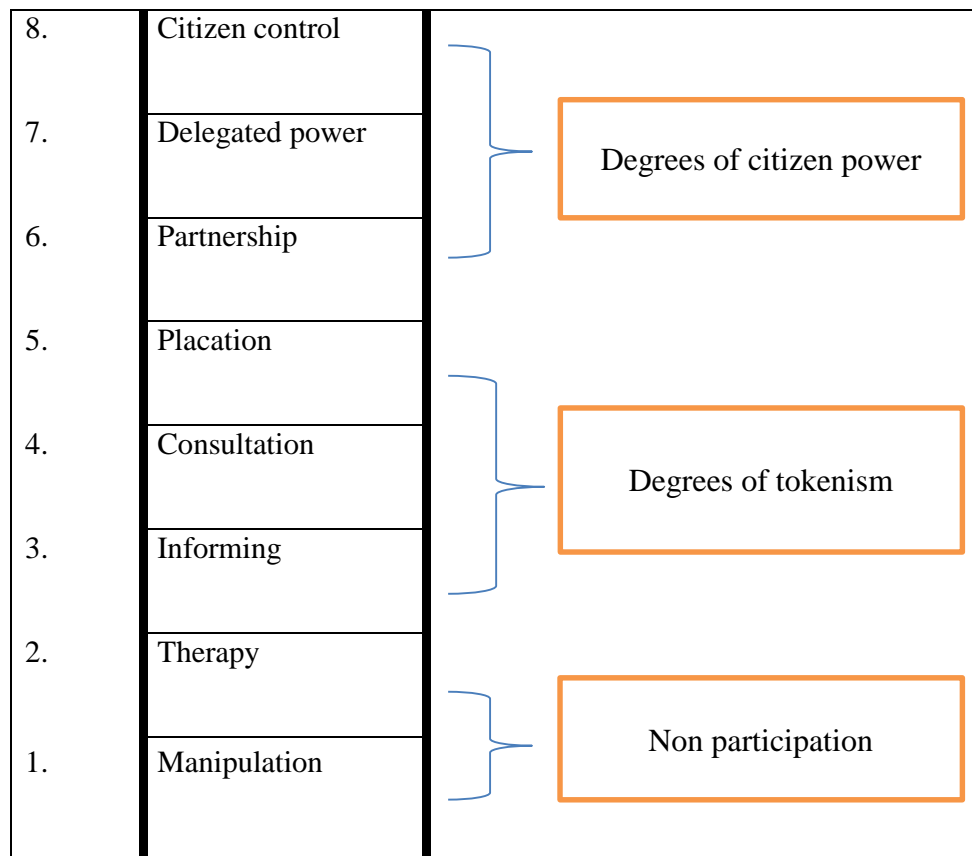


Figure 1. Arnstein's ladder of participation (Arnstein 1969)

In the model proposed by Arnstein (1969), participation only occurs at the highest rungs of the ladder, where power is transferred to the consumer. There have been various critiques of this framework as many have considered it to be over-simplified (Charles & DeMaio 1993; Feingold 1977; Sleath & Rucker 2000; Tritter & McCallum 2006). Charles and DeMaio (1993) developed a more sophisticated participation model consisting of three domains: *decision-making*, *role perspective*, and the *level of participation*. In the

decision-making domain there are three levels of decisions a service user may choose to be involved in: decisions at an individual level, decisions at a service delivery level, and decisions at a policy level (Charles & DeMaio 1993). Within the *role perspective* domain, consumers can be involved as a service user or from a public policy perspective (Charles & DeMaio 1993). The *level of participation* domain is a more compressed version of Arnstein's (1969) ladder, with three subdomains rather than eight, which include: *consultation*, *partnership* and *dominant lay control*. Charles and DeMaio (1993) deleted the first three rungs on Arnstein's ladder as they considered these to be levels of non-participation, combining *placation* and *consultation* into one subdomain called *consultation*, and combining *delegated power* and *citizen control* into one subdomain called *dominant lay control*. A criticism of Arnstein's ladder is that it fails to recognise that the type of decision and role perspective of the consumer are also significant parameters alongside the level of participation in a participation framework (Charles & DeMaio 1993; Sleath & Rucker 2000). Tritter and McCallum (2006) also argue that Arnstein's model places too much emphasis on the transfer of power and fails to acknowledge the importance of agency. If consumer participation is to succeed, individuals must possess agency and the ability to shape the actual processes which facilitate their involvement (Tritter & McCallum 2006). Additionally, structures and practices must also be in place to empower and facilitate consumer participation at four levels: the healthcare system, the organisation, the community and the individual (Tritter & McCallum 2006).

Consumer participation is a complex phenomenon which is dependent upon a wide range of factors such as the type of decision (i.e. decisions concerning the individual, the service or health policy), the role of the consumer (as a service user or a person interested in public policy), the level of participation, the agency of the consumer, and the structures

and processes which may facilitate or constrain consumer participation (Tritter & McCallum 2006). For the purposes of this study, the definition of ‘decision’ was limited to those made at an individual level from the perspective of the service users. Therefore, the elements of participation explored in the study were the levels of participation in individual decision-making, the agency of the service user, and the structures and processes which may facilitate or constrain consumer participation.

Agency

Similar to participation, no clear definition for the term agency exists, such that it has become a ‘*slippery concept*’ (Hitlin & Elder 2007, p. 171) and ‘*a source of increasing strain and confusion in social thought*’ (Emirbayer & Mische 1998, p. 962). One of the most prominent theoretical definitions states that agency is the:

...temporally constructed engagement by actors of different structural environments – the temporal relational contexts of action – which, through the interplay of habit, imagination, and judgement, both reproduces and transforms those structures in interactive response to the problems posed by changing historical situations. (Emirbayer & Mische 1998, p. 970)

These authors viewed agency as a chordal triad constituted of three different analytical elements: iteration, projectivity and practical-evaluation. These elements are oriented towards the past, future and present respectively, and as such all forms of agency are temporally embedded in the flow of time (Emirbayer & Mische 1998). The iterational element is defined as an actor’s ability to recall previous patterns of thought and action, which is used to influence current action (Emirbayer & Mische 1998). This past orientation helps to provide stability and maintain the actor’s identity over time (Emirbayer & Mische 1998). The projective element is defined as an actor’s ability to imagine their future trajectory, in which action is influenced by their hopes, fears and desires for the future (Emirbayer & Mische 1998). The practical-evaluative element is defined as an actor’s ability to weigh up the pros and cons of an action in response to the

demands or dilemmas of a presently evolving situation (Emirbayer & Mische 1998). An individual may exert different elements of agency in response to a situational challenge, and in any given situation one or more of these elements may predominate (Emirbayer & Mische 1998; Hitlin & Elder 2007).

Moreover, Campbell (2009) highlights that agency is not confined solely to the self but is also dependent on the power of social structures; Campbell views agency as similar to power, insofar as power is an *'individual's ability to do so against resistance'* while agency is the *'ability of individuals to implement their will'* (Campbell 2009, p. 409). Campbell (2009) argues that the concept of agency possesses two forms: Type 1 and Type 2. Type 1 is referred to as the power of agency and is defined as *'the actor's ability to initiate and maintain a program of action'*, while Type 2 is referred to as agentic power and is defined as *'the actor's ability to act independently of the constraining power of social structure'* (Campbell 2009, p. 407). Therefore, when examining agency it is crucial not only to assess a person's *ability* to act but also to consider whether they have the *freedom* to act (Campbell 2009). In summary, the ability to exert action is dependent upon a person possessing both the ability (power of agency) and the freedom to operate independently from constraining social structures (agentic power).

Most sociological theories, like Campbell's (2009) and Emirbayer and Mische's (1998), do not consider the social psychological perspective even though this perspective can add to the above theory of agency (Hitlin & Elder 2007). The social psychological scholar Bandura (2001) identified four aspects of agency: intentionality, forethought, self-reactiveness and self-belief. Bandura (2001) considered self-belief to be a critical component of human agency, as an individual may possess power of agency and agentic power, but unless the person has a belief in their own capacity, no action will occur. Therefore, how a person perceives themselves in a cultural context has a significant

impact on their agentic power and all of these factors may influence the ability of the person WDLA to participate in the decision-making process.

Political framework for participation in Australia

Despite a lack of consensus around consumer participation there have been increasing calls in the Western World to engage consumers in decisions about their own health and the healthcare system (Thompson 2007). In Australia, consumer participation in healthcare has a history that can be traced back to 1987, when the Consumer Health Forum of Australia (CHF) was formed (Consumers Health Forum of Australia 2011a). The CHF, funded by the Department of Health, is the national peak organisation representing consumers on national health care issues. The aim of the CHF is to provide a national voice for the interests of consumers and to support consumer participation in health policy and program decision-making (Consumers Health Forum of Australia 2011b). The strength of the consumer movement has led to increasing consumer demands for choice and participation within the healthcare system (Aston et al. 2009).

In 2001, the Consumer Focus Collaboration (CFC), a national Australian body with representatives from consumer, professional and private sector organisations and all State and Federal health departments, published a document summarising the evidence supporting consumer participation. The report predominantly relied on data from quantitative studies of people with chronic diseases to argue that active consumer participation in decision-making leads to improved health outcomes (Consumer Focus Collaboration 2001). The CFC was also of the view that consumer participation leads to a more accessible and effective health service and is fundamental to the success of any health strategy or program (Consumer Focus Collaboration 2001). It was acknowledged however, that effective consumer participation depends on access to quality information and the adoption of a range of methods to facilitate the participation of those most

marginalised by mainstream healthcare services (Consumer Focus Collaboration 2001). Another review of the literature concluded that participation by more marginalised groups is an important way of identifying and overcoming barriers to accessing healthcare services (Commonwealth Department of Health and Aged Care 2000). These reviews were pivotal to the adoption of consumer participation initiatives in Australian healthcare legislative policy documents (Consumers Health Forum of Australia 2011a).

On 1st January 2006, the Australian State and Territory Governments established the Commission on Safety and Quality in Healthcare which was aimed at improving health service provision with consumer participation as a key priority (Australian Commission on Safety & Quality in Healthcare 2011). In response, the Commission developed the Australian Charter of Healthcare Rights, applicable to all healthcare settings, which strongly mandates consumers' right to be included in the decision-making process (Australian Commission on Safety & Quality in Healthcare 2008). In addition, in 2011, the National Safety and Quality Health Service Standards and Accreditation Scheme was established; one of the ten standards is titled 'Partnering with Consumers' and specifically requires healthcare services to address effective and meaningful consumer participation.

In the aged care sector, participation is also strongly endorsed in the legislative framework. In 2009, the then Department of Health and Ageing (now called the Department of Health) published the Charter of Rights and Responsibilities for Community Care. This Charter applies to people in receipt of Australian Government funded packages legislated under the *Aged Care Act 1997* (Australian Government ComLaw 2009). The Charter advises that consumers have the right to participate in decisions affecting their lives and to be involved in identifying and choosing the care and services that best meet their needs. In the absence of capacity, the consumer may appoint

a person to represent them in decisions affecting their lives (Australian Government ComLaw 2009).

In recent years, advocacy has also become an influential concept in healthcare reforms and policies in many countries (Jugessur & Iles 2009). Under the *Aged Care Act 1997*, and the principles that flow from it, the Australian Government established the National Aged Care Advocacy Program (NACAP) (Australian Government Department for Health & Ageing 2011). Independent community-based organisations (Advocacy Services) are funded by the Australian Government through NACAP to provide a free and confidential service promoting the rights of people receiving Australian Government subsidised aged-care services. The aims of the program are to protect the rights of consumers of aged-care services, including their right to participate in their own decisions, and to contribute to improvements in the quality of life of aged care service users (National Advocacy Aged Care Program 2011).

Along with the advocacy program and the establishment of policies on participation in decision-making, there is also a significant shift toward providing greater flexibility and choice for consumers of aged-care services (Australian Institute of Health & Welfare 2012). As part of the 2011-12 Federal Budget funding for health and aged-care, flexible funds were introduced to provide greater choice to consumers receiving community care packages (Australian Institute of Health & Welfare 2012). In Australia, dementia is a condition which falls under the responsibility of aged care and its associated legislative frameworks (Australian Government Department for Health & Ageing 2011). In April 2012, the Australian Government released an aged care reform package entitled 'Living longer, living better'. Part of this package was \$268.4 million over five years for dementia-related programs and services (Australian Institute of Health & Welfare 2012). The purpose of the reform package is to increase choice and the level of support for

people with dementia living in the community with an overall aim of increasing the amount of time individuals with dementia can remain living in the community.

Although consumer participation is a central facet of Australian legislative policies in relation to health and aged care, Gregory (2008) found that it is poorly understood, inconsistently practiced and under-theorised. Consistent with these findings, Browne and Hemsley (2008) found that in practice, levels of consumer participation – particularly for marginalised groups – are low and that more progress is needed. Gregory (2008) was of the view that the practice of consumer participation depends upon two factors: a strong commitment from the service organisation, and the confidence of the consumer that their input will be valued and considered. These factors may be difficult to attain with more marginalised groups. For instance, Clare and Cox (2003) reported that marginalised groups, such as those with cognitive difficulties, are seen as more difficult to involve and are therefore often excluded. Also, the nature of dementia makes people experiencing the condition particularly vulnerable to exclusion when decisions are being made about their present and future needs (Wells 2006). People WDLA are considered one of the most marginalised groups in society (Bamford & Bruce 2000; Dewing 2002; Wilkinson 2002). Browne and Hemsley (2008) believed that structural changes and a fundamental shift in health professionals' attitudes are required if people from more marginalised groups in society are to participate in the decision-making process.

Advocacy for people WDLA

Dementia is a condition which gradually destroys a person's short-term memory and a person's ability to think, reason and make rational decisions (Wells 2007). Its progression is usually slow and lacking in uniformity, and a person's abilities may fluctuate on a day-to-day basis (Wells 2007). In spite of the often prolonged and insidious nature of this decline there remains a pervasive belief that once diagnosed a person with dementia is

immediately and permanently rendered ‘mentally incompetent’ and incapable of making decisions (Beattie 2009; Boyle 2010). Because of these and similar misconceptions it is often assumed that people with dementia are too unreliable, too confused or too removed from reality to be included in participation initiatives (Cotrell & Schulz 1993; Goldsmith 1996; Whitlatch & Menne 2009). The evidence suggests that even in the early stages, despite their ability to participate, people with dementia are often excluded from decisions about their care (Horton-Deutsch, Twigg & Evans 2007; Tyrrell, Genin & Myslinksi 2006). This perspective tends to leave the person effectively marginalised, voiceless and vulnerable to social exclusion (Boyle 2008; Waugh, F 2009).

People WDLA are reported to be at even greater risk of being excluded from the decision-making process (Boyle 2010). In recognising this risk, the United Kingdom, under the *Mental Capacity Act 2005*, was the first country to provide legislative guidance aimed at protecting and maximising the rights of people WDLA to participate in decision-making (Boyle 2010; *Mental Capacity Act 2005*; Redley et al. 2009). This Act, applicable in England and Wales, specifies that capacity must be determined before decisions are made on behalf of another person, and that any decision made must have regard for his or her best interests (Boyle 2010). In addition, under the Act a new Independent Mental Capacity Advocate (IMCA) Service was introduced to provide help for people who lack capacity but have no personal support network to speak on their behalf (Boyle 2008; Department of Health 2007; Redley et al. 2009). Although, the *Mental Capacity Act 2005* enshrined the first legal right to advocacy for those who may lack decisional capacity in England and Wales, its scope is limited to decisions about serious medical treatment or changes in the person’s accommodation. Calls to make advocacy universally available for all decisions were rejected on the grounds of cost and practicality (Gorczyńska 2007; Redley et al. 2009). In the UK it falls upon non-government dementia advocates to

support people WDLA with a much wider range of everyday issues (Boyle 2010; Wells 2006). An evaluation of the pilot IMCA service found that in more than half of the decisions evaluated (54 per cent of the 109 completed cases), clients were able to provide some indication of their wishes, thus enabling them to participate directly in personal decisions (Redley et al. 2009). In this study, 33 per cent of all clients suffered from dementia (Redley et al. 2009).

In Australia, advocacy is also recognised as a way to promote the rights of marginalised groups. As previously stated, independent, community-based advocacy organisations are funded by the Australian Government to provide a free and confidential service to promote the rights of people receiving Australian Government subsidised aged-care services. In Tasmania, Advocacy Tasmania Inc. (ATI) is responsible for offering this service as well as advocacy services to people WDLA. The expressed purpose of this advocacy service is:

to support people with memory loss and dementia to make their own decisions and continue to manage their lives so that they can remain living successfully in the community for as long as possible. (Advocacy Tasmania 2010)

In June 2013, the Australian House of Representatives Standing Committee on Health and Ageing published the findings of an inquiry entitled ‘Dementia: Early diagnosis and intervention’ (House of Representatives Standing Committee on Health and Ageing 2013). One of the recommendations of this inquiry was the provision of dementia link workers to assist in the ongoing case management of people with dementia and their carers from the time of diagnosis throughout the progression of the condition. The report suggested that the primary role of these link workers should be to provide support, advice and advocacy for people with dementia and their families (House of Representatives Standing Committee on Health and Ageing 2013). It is not clear from the inquiry’s report

whether this position would replace or complement existing independent advocacy services for people WDLA.

Advocacy for people with dementia is in its infancy as it has only recently been seen as both possible and desirable for people with dementia to engage in advocacy (Goldsmith 1996; Wells 2006). Wells (2007) found that many dementia advocates are working in an area where there is limited practice guidance and little research evidence. Although there are numerous descriptive examples of advocacy schemes, research-based critical evaluations are rare (Cantley & Steven 2004; Manthorpe & Martineau 2010). Cantley, Steven and Smith (2003) identified a need for research that improves understanding of what people with dementia require from advocacy services, including their experience of these services and their effectiveness in enabling people with dementia to achieve greater influence in the decision-making process. Cantley and Steven (2004) recommended that research should elicit the perspectives of families, other service providers and people with dementia. However, there appears to be a reluctance to engage people with dementia – particularly people WDLA – in research; the following section explores some of the reasons for this exclusion.

Participation of people WDLA in research

Until the late 1990s, social research implicitly sustained the marginalisation of people with dementia by focusing on proxy reports of carers while excluding the voices of people with dementia (Bamford & Bruce 2000; Beuscher & Grando 2009; Bond & Corner 2001; Dewing 2002; Goldsmith 1996; Hellström et al. 2007; Livingston et al. 2010; Mozley et al. 1999; Van der Roest et al. 2009; Waugh, F., Napier & Bonner 2004). People with dementia were viewed as '*passive actors*' (Brannelly 2011, p. 663) and perceived as incapable of providing reliable accounts because of their memory and verbal communication deficits (Cotrell & Schulz 1993; De Boer et al. 2007; Nygård 2006). From

the late 1990s there was widespread concern about the reliance on proxy accounts and the limited extent of the involvement of people with dementia in research (Bartlett & Martin 2002; Clarke, CL & Keady 2002). Since then, studies have demonstrated that people with mild to moderate levels of cognitive impairment can provide accurate and consistent responses to questions on the nature of the care, care preferences and care services provided (Bamford & Bruce 2000; Cotrell & Schulz 1993; Feinberg & Whitlatch 2001; Mozley et al. 1999; Whitlatch & Menne 2009). Moreover, research has found that carers' perceptions of the person with dementia's values and preferences for care often differ from the values and preferences actually held by the person in question (Cahill et al. 2004; Feinberg & Whitlatch 2001; Phinney 2002). In addition, carers were found to score the subjective quality of life of the person with dementia significantly lower than the person themselves (Bárrios et al. 2013; Cahill et al. 2004). Several authors suggest that listening to people with dementia not only provides a deeper understanding of their care needs and preferences, but also increases their feelings of self-worth and validates their contribution to research (Barnett 2000; Clarke, CL & Keady 2002; Dewing 2002; McKeown et al. 2010; Phinney 2002; Van der Roest et al. 2009). As Robinson (2002), who has dementia, wrote:

What a hugely missed opportunity it would be if people with Alzheimer's were excluded from the very thing that could be used to gain a fuller understanding of their disease. It would be simply denying us the chance to fill the gaps that no one else can. I also know that the research I have taken part in so far will not benefit me personally but taking part in it has lifted my morale. (Robinson 2002, p. 104)

Since the late 1990s, the number of studies involving people with dementia has increased dramatically, although it is still rare for people with dementia to participate (Gould et al. 2010; Soniat 2004). This under-researched group has become a major concern following the increasing trend in the number of older people living alone, along with the rising numbers

of people with dementia (Sait 2013; Tierney, Charles, Snow, et al. 2001). Factors contributing to the limited research in this population have been explored by several authors (Bartlett & Martin 2002; Hellström et al. 2007; McKeown et al. 2010). Hellström et al. (2007) deemed that one of the first major difficulties to overcome in research with this cohort is the existence of so-called '*gatekeepers*' (p. 612), such as ethics committees, family carers and primary care physicians. These '*gatekeepers*' often make decisions on behalf of the person with dementia and make personal judgements as to whether the individual may or may not participate in a particular project (Hellström et al. 2007). Obtaining '*gatekeeper*' approval is an essential precondition of study progression and the need to negotiate with these '*gatekeepers*' may deter researchers from engaging in dementia research (Bartlett & Martin 2002; Hellström et al. 2007; McKeown et al. 2010).

Another potential deterrent to involving people with dementia in research is the complexity of the consent-giving process, particularly for those who live alone (Dewing 2002). When obtaining consent, a researcher must ensure that a potential participant has the capacity to understand the information given so as to ensure that their consent is valid (McKeown et al. 2010). To address this concern, an ethics approval may require a family carer or another significant person in the participant's life to verify the consent process (Hellström et al. 2007). Although this independent verification is aimed at protecting the rights of the individual concerned, it may result in the exclusion of people without an identifiable carer (Soniati 2004). A further challenge when designing research studies with cognitively impaired individuals is that often extra steps are required to ensure the reliability of the data they provide (Soniati 2004). This issue of reliability is frequently addressed by ensuring the presence of a family carer or a significant other during the interview with the cognitively impaired individual. Once again this method may result in the exclusion of those without an identifiable carer from research projects (Soniati 2004).

These issues are significant: it is estimated that 30 per cent of people WDLA have no identifiable informal carer (Webber, Fox & Burnette 1994).

A further challenge in dementia research is that studies have shown that people living alone are less likely to be diagnosed with dementia, and this reluctance to diagnose dementia may contribute to the small numbers of people WDLA who participate in dementia research (Lopponen et al. 2003; Soniat 2004). By the time individuals are diagnosed with dementia, there is a risk that they may have progressed too far along the dementia trajectory to have the capacity to participate in research (Lopponen et al. 2003). Another issue which has been found in studies of this population group is their reluctance to participate in research. Researchers have found recruitment particularly challenging, as many of the people approached feared that their participation in research may lead to a loss of independence, autonomy and personal agency (Soniat 2004; Tierney et al. 2004). All of these issues need to be overcome if people WDLA are to actively participate in research.

Research Design

Policies exist in most Western countries to ensure that consumers are involved in decision-making about their own healthcare, and it is widely acknowledged that this involvement can result in improved overall well-being for consumers. Nonetheless, there is concern that marginalised groups, such as those with dementia living alone, are largely excluded from consumer participation initiatives (Church et al. 2002). There is a clear need for such people to have their voices heard in the critical decisions that are being made about their lives and their futures (Wells 2006). People WDLA are particularly vulnerable to exclusion even though this group makes up approximately one third of people with dementia living in the community (Ebly, Hogan & Rockwood 1999; Tuokko, MacCourt & Heath 1999; Webber, Fox & Burnette 1994). Members of this group are also

more likely to be socio-economically disadvantaged and less likely to use services, thereby increasing their risk of marginalisation in the decision-making process (Ebly, Hogan & Rockwood 1999; Tuokko, MacCourt & Heath 1999; Webber, Fox & Burnette 1994). In recent years, advocates have made some progress towards facilitating their participation in decision-making although questions remain on how advocates can best assist people WDLA in this process throughout the various stages of dementia (Cantley, Steven & Smith 2003).

The overarching aim of this research is to explore the power of people WDLA to participate in decision-making processes with advocacy support. To address this aim the following questions were examined:

- How does dementia impact on the agency of people WDLA?
- What are the factors influencing agentic action of people WDLA?
- What are the features of advocacy that facilitate participation of people WDLA in the decision-making process?

This research strengthens our knowledge of people WDLA's participation in decision-making processes and the role advocacy plays in promoting their involvement. Furthering knowledge and understanding in this area will ultimately improve the quality of life of people WDLA as it can lead to greater inclusion in decisions about their own care and service needs.

Research methodology

A critical realist theoretical perspective was taken for this study as critical realism offers a stratified meta-theory which focuses on the relationship between social structures and human agency (Angus et al. 2006). Critical realist researchers consider both agency and

structures to be related but separate entities, with their own properties and causal efficacy (Angus et al. 2006). Structures can be viewed as the conditions or context of people's lives, while agency is the ability of individuals to intentionally bring about change in their lives (Angus et al. 2006). The interplay between these two strands is of great importance and relevance when examining participation of people WDLA because social structures provide the conditions that can either facilitate or constrain inclusion, and individuals always operate within a pre-existing context (Angus et al. 2006). However, to date, studies with people WDLA have predominantly focused on their experiences of living with dementia (Kontos et al. 2010). To maximise consumer participation, the structures which constrain and enable participation and the capacity of people WDLA's to affect social structures also need to be explored (Kontos et al. 2010; O'Connor, D, Purves & Downs 2009).

Critical realism, founded by Roy Bhaskar (1975), combines a realist ontology (theory of being or nature of reality) with a relativist epistemology (theory of knowledge). One major tenet of critical realism is that ontology is made up of three domains: empirical, actual and real (Bhaskar 1975). The empirical domain consists of what is experienced, either directly or indirectly, and events that may have occurred in the world but which may have no effect on a person. The actual domain is where an event occurs; in simple terms it is what happens in the world. The real domain is where mechanisms produce an event or cause something to happen in the world – these are called generative mechanisms (Bhaskar 1975). Generative mechanisms include the structures, powers and relations that explain how things work, which may or may not be observable (McEvoy & Richards 2003). Critical realists believe that in order to acquire knowledge, the causal mechanisms that produce the actual events (or phenomena) must be understood by examining the empirical layer (experiences) (McEvoy & Richards 2003). Advocacy is a

phenomenon that is employed to facilitate participation and a critical realist approach was used to examine why advocacy may or may not facilitate agency of people WDLA, by exploring the empirical layer and theorising on the underlying generative mechanisms that operate in different circumstances (contexts) (Pawson & Tilley 1997).

A predominantly qualitative research method was used in this study to enable the researcher to explore issues from the perspective of the individuals directly involved in the phenomenon (Hansen 2006). Qualitative methodology is well suited to critical realism because it provides a deeper understanding and explanation of social phenomena (Given 2008; Silverman 1997). Semi-structured in-depth interviews were conducted with nine people WDLA living in Tasmania, all of whom had used the advocacy service within the previous six months. Semi-structured interviews were conducted with the four advocates working with these clients. Three focus groups and three semi-structured interviews were conducted with 21 healthcare professionals. The groups were composed of healthcare professionals involved in meeting care-assessment needs and with referring people WDLA to the advocacy service. These professionals included medical practitioners, geriatricians, social workers, ACAT assessors and allied healthcare professionals. Danermark's (2002) model of abduction and retroduction was used to analyse the data and guide the research in the search for underlying mechanisms influencing the agentic action of people WDLA.

In addition to the interviews, nine people WDLA were asked to complete a short validated quality of life questionnaire (QOL-AD), while the advocate was also asked to complete a QOL-AD on behalf of each client involved in the study. Quality of life (QOL) has recently been recognised as an important element in ascertaining the actual impact of a disease. Further, participation in decision-making is reported to increase QOL of people with dementia (Cahill et al. 2004; Wetherell & Wetherell 2008). In spite of the growing

importance of measuring QOL, no specific studies measuring the QOL of people WDLA were identified (Moyle et al. 2007). The QOL-AD tool used in this study is recommended by the Australian Government for measuring dementia-specific health-related quality of life (Sansoni et al. 2007).

Thesis structure

The thesis is organised into seven chapters. This chapter discussed the prevalence and characteristics of people WDLA, defined consumer participation and agency, discussed the political framework supporting participation in health, and presented a brief overview of the research methodology and study design. Chapter Two presents a review of the literature on people WDLA and dementia advocacy, identifies the gaps in this literature and provides a justification for the research questions. The review identifies significant gaps in relation to the impact of dementia on agency of people WDLA, their ability to participate in the decision-making process and the role of dementia advocates in facilitating participation. Chapter Three outlines the theoretical framework, the research design, and the methodology chosen for this study and discusses the data analysis methods used to identify the generative mechanisms. Chapter Four and Chapter Five present the results of the research. Chapter Four presents the results from the QOL-AD questionnaire and the semi-structured interviews from people WDLA focusing on the impact of dementia on agency and decision-making. Chapter Five discusses the findings on dementia advocacy and presents the benefits of, and barriers to, dementia advocacy. Chapter Six provides a synthesis and discussion of the overall findings of this thesis, theorising on the generative mechanisms underpinning the actual and empirical events. Chapter Seven provides an overall conclusion to this research and presents recommendations on the participation of people WDLA in the decision-making process and the future direction of the dementia advocacy service.

Chapter 2: Literature Review

Introduction

This chapter provides an analysis of the current literature on people WDLA and explores what is known about dementia advocacy. The initial scope of the review was decision-making for people WDLA, but due to the limited number of articles published in this area the scope was broadened to include decision-making for people with dementia and research on people WDLA. The time period for the review was also extended beyond the normal ten year period to ensure all relevant material on people WDLA was captured. Research incorporating people WDLA is limited because up until the 1990s it was incorrectly assumed that few people with dementia lived alone (Webber, Fox & Burnette 1994).

Initial research into this population focused on establishing demographics, characteristics and service utilisation, the results of which were presented in Chapter One and are not discussed further in this chapter. From early 2000 to 2005, safety of people WDLA appeared to be the predominant theme in the literature, while from 2005 onwards, attention began to be concentrated on the needs of this cohort. During this period, and in recent research, the focus shifted to understanding the experiences of living alone with dementia from the perspective of the person with dementia. This review examines the findings of these studies and identifies the gaps in the literature for this cohort. Literature on dementia advocacy is extremely limited and the scope of the review was broadened to include advocacy for older persons and advocacy for older people with mental health issues, and the key findings and gaps identified in the literature are also presented in this chapter.

Published articles were accessed using electronic bibliographic databases including Web of Science, Medline and CINAHL. Relevant literature was also identified using a 'snowball' approach where references cited in key articles were reviewed and any article citing a primary reference was also assessed for relevance. Policies and reports relevant to the study were also a key source of information.

This chapter begins with a review of the literature on participation of people WDLA in the decision-making process. Following this the review examines the findings of the studies on the safety, needs and experiences of people with dementia living alone and identifies the gaps in the literature for this cohort. The chapter then proceeds to review the literature on advocacy and discusses the benefits of, and barriers to, advocacy involvement and the complexities associated with dementia advocacy. The chapter concludes with a justification of the research questions for this study.

Participation in decision-making

Literature on decision-making of people with dementia, particularly those who live alone, is not extensive, and much of what is available relates to decision-making capacity (Feinberg & Whitlatch 2001; Kim, Karlawish & Caine 2002; Whitlatch & Menne 2009).

A total of 149 papers on decision-making with dementia were reviewed, and of these 25 studies were deemed relevant to this review and are discussed further in this section. Kim, Karlawish and Caine (2002) conducted a review of 32 empirical studies on decision-making capacity of elderly people with dementia or a cognitive impairment found that although dementia impairs decision-making capacity, a diagnosis of dementia does not equate to a total lack of capacity. In fact, researchers have found that decision-making capacity depends upon the severity of dementia and the insight of the person with dementia (Menne et al. 2008; Samsi & Manthorpe 2013). Kapp and Mossman (1996) also discovered that capacity is not uniform, in that a person with dementia may be capable of

making decisions about various aspects of their care while at the same time being unable to make other decisions, such as those about financial matters. Feinberg and Whitlatch (2001) found that individuals with mild to moderate levels of cognitive impairment have the ability to respond consistently to questions on their preferences and to be involved in decisions about their daily lives. Research clearly indicates that people with mild to moderate dementia can possess the ability to participate in the decision-making process.

Numerous studies also highlighted that it was extremely important for the majority of people with dementia, including those with WDLA, to be involved in decisions affecting them for as long as possible (De Witt, Ploeg & Black 2009; Fetherstonhaugh, Tarzia & Nay 2013; Frazer, Oyebode & Cleary 2012; Harris 2006; Hirschman et al. 2005; Tyrrell, Genin & Myslinksi 2006). In addition, greater well-being and improved quality of life were associated with involvement in everyday decision-making for people with dementia (Menne et al. 2008). Despite their ability and desire to participate, and the perceived benefits for people with dementia, many authors reported that people with dementia, even in the early stages of the disease, were denied the opportunity to participate in the decision-making process (Boyle 2008; Horton-Deutsch, Twigg & Evans 2007; Tyrrell, Genin & Myslinksi 2006; Whitlatch & Menne 2009). For example, Horton-Deutsch, Twigg and Evans (2007) combined the results of semi-structured interviews with older adults with mild to moderate dementia with data obtained from a quantitative portion of a larger study, to examine their experiences of the healthcare decision-making process. The authors found that older adults with mild to moderate dementia had the ability to participate in the healthcare decision-making process and to provide reasonable justifications for their choices (Horton-Deutsch, Twigg & Evans 2007). Notwithstanding this, the study showed that carers easily overruled the wishes of the person with dementia

and that this response did not necessarily correlate with the level of cognitive impairment (Horton-Deutsch, Twigg & Evans 2007).

Whitlatch (2001) suggested carers may find having complete control over decisions less stressful than having to spend time explaining the different options to the person with dementia. Furthermore, although involvement in the decision-making process increased quality of life and decreased depression for people with dementia, the converse was found to be true for carers (Whitlatch 2001). These results may provide an explanation of why some carers exclude people with dementia from the decision-making process. Therefore carers can contribute to the marginalisation of people with dementia in the decision-making process.

Various authors have suggested that once a person is diagnosed with dementia, others around them, including healthcare professionals, family and friends, often perceived the person with dementia as being incapable of making decisions (Batsch & Mittelman 2012; Beattie 2009; Brannelly 2011; Tyrrell, Genin & Myslinksi 2006). For example, Brannelly (2011) conducted a qualitative study, using a social constructionist and critical realist approach, to explore whether healthcare professionals facilitated the participation of people with dementia and their families in their care. Observational studies with 15 healthcare professionals working with 50 people with dementia and their families were carried out (Brannelly 2011). Observational results indicated that some healthcare professionals made no attempt to engage people with dementia in the decision-making process, regardless of the person's ability to participate, nor did they take into account the person's preferences or the needs of their families. Additionally, any emotional reaction shown by people with dementia was ignored and rationalised in terms of their illness (Brannelly 2011). Similar to the previous study by Horton-Deutsch, Twigg and Evans

(2007), Brannelly (2011) showed that some healthcare professionals also excluded people with dementia from involvement in healthcare decisions.

In addition to healthcare decisions, three further qualitative studies were identified which explored the perspectives of people with dementia in everyday decision-making (Fetherstonhaugh, Tarzia & Nay 2013; Samsi & Manthorpe 2013; Tyrell, Genin & Myslinksi 2006). Tyrell, Genin and Myslinksi (2006) conducted interviews with 21 older people with dementia, of whom six were living alone, to explore their level of participation in a recent decision (to accept professional help at home, to attend a day centre or to move to residential care). The study found that the majority of people with dementia did not feel adequately listened to by either professionals or family carers, and that their opportunities to participate in the decision-making process were very limited. Furthermore, participants felt they were not provided with sufficient information to make a choice, nor were they given enough time to consider the decision. Additionally, participants felt that there was no possibility to change their minds once a decision was made. Consistent with the findings of the studies by Horton-Deutsch, Twigg and Evans (2007) and Brannelly (2011), Tyrell, Genin and Myslinksi (2006) showed that older people with dementia were not being heard and were being marginalised in the decision-making process by both family carers and healthcare professionals.

Fetherstonhaugh, Tarzia and Nay (2013) conducted interviews with six people with dementia living in the community to explore the meaning of decision-making, using a phenomenological approach. No information was provided on the living arrangements of the participants. The study highlighted the importance for people with dementia of remaining central in the decision-making process (Fetherstonhaugh, Tarzia & Nay 2013). In addition, carers were found to possess the ability to enable or disable the involvement of people with dementia in the decision-making process (Fetherstonhaugh, Tarzia & Nay

2013). Key to this was the way carer support was provided; if offered subtly, such that people with dementia still felt in control of the decision, support was welcomed and accepted, while if support was forced, or if the person with dementia perceived they were being marginalised, people with dementia reacted negatively and became resentful (Fetherstonhaugh, Tarzia & Nay 2013).

Moreover, Sami and Manthorpe (2013), in their longitudinal study with 12 dyads (the person with dementia and their carer), found that as the disease progressed, the carers' role changed in the decision-making process. Carers moved from a supportive role during the early stages of the disease to becoming a substitute decision-maker when the person with dementia lost decision-making capacity in the later stages of the disease (Samsi & Manthorpe 2013). However, carers were found to struggle with two aspects of this change: firstly the task of determining the decision-making capacity of the person with dementia, and secondly; weighing up what was in the best interest of the person with dementia (Samsi & Manthorpe 2013). A difficulty for carers is the lack of a universal tool to assess capacity, meaning that assessments are often subjective (Lai & Karlawish 2007; Lowe et al. 2000). Difficulty with these subjective judgements is not restricted to carers alone, Lowe (2000) found that assessments of capacity may even differ between clinical experts for the same patient. In worst case scenarios, lack of appropriate capacity assessments has led to people with dementia being detained in residential care facilities against their wishes (Boyle 2008; Brannelly 2006; Webber, Fox & Burnette 1994). Lai and Karlawish (2007) have called for further research aimed at developing and implementing effective capacity assessments for services which provide people with dementia the opportunity to participate in the decision-making process.

As discussed in Chapter One, the United Kingdom was the first country to provide legislative guidance on assessing capacity with the *Mental Capacity Act 2005*, which

includes provisions to maximise the participation of people with dementia in the decision-making process (Boyle 2008, 2010; Mental Capacity Act 2005; Redley et al. 2009). The Act recognises that a person with dementia may have the capacity to make one decision but may be unable to make another; consequently, capacity must be assessed as each decision arises (Wells 2006). Similarly to the United Kingdom, Australia has also recently recognised a need for guidance on capacity assessments. In June 2013, the House of Representatives Standing Committee on Health and Ageing published a report on an inquiry into dementia which recommended the development of uniform definitions and guidelines relating to capacity (House of Representatives Standing Committee on Health and Ageing 2013). These guidelines may help to overcome the difficulties faced by those involved in the assessment of capacity. Future research is required to assess the impact of these legislative frameworks and any such research should include the perspectives of the person with dementia.

Although these studies provided valuable insight into the complexity of capacity assessments and the participation (or lack of participation) of people with dementia in the decision-making process, there is a major gap in the literature on the experiences of people WDLA, particularly those without a family carer. Tyrrell, Genin and Myslinksi (2006) included people WDLA in their study, however no comparison was made between the experiences of those living alone and those co-residing. This is significant given that people WDLA are reported to be at greater risk of exclusion from the decision-making process (Webber, Fox & Burnette 1994). The absence of research on the participation of people WDLA has previously been highlighted by Sami and Manthorpe (2013), who have called for further studies on how people WDLA negotiate everyday decisions. This gap is growing in significance given that the number of people WDLA is increasing (Samsi & Manthorpe 2013).

Furthermore, existing research has predominantly explored issues of capacity and the meaning of participation, but has failed to examine the impact on, or response of, the person with dementia to their loss of participation in the decision-making process. There is also an absence of perspectives from people with younger onset dementia, as the majority of studies have only included the experiences of older people with dementia in the decision-making process. In addition, existing research has shown that others, such as carers and healthcare professionals, can influence the involvement of the person with dementia in the decision-making process, but factors or mechanisms which enable or disable their participation have not been specifically addressed.

Safety of people WDLA

Since the early 2000s, as people became aware of the number of people WDLA, a strong concern for their safety emerged, and research began to focus on risks and predictors of risks for this cohort (Gilmour 2004; Tierney et al. 2004; Tierney, Charles, Snow, et al. 2001). The key risks identified for people WDLA include: malnutrition, self-neglect, injury, medication errors, and financial abuse (Abrams et al. 2002; Cooper et al. 2005; Edwards & Morris 2007; Gould et al. 2010; Heath et al. 2005; Miranda-Castillo, Woods & Orrell 2010; Nourhashemi et al. 2005; Tierney et al. 2004; Tierney, Charles, Snow, et al. 2001; Yaffe et al. 2002). People WDLA were also found to be less likely to recognise their own cognitive impairment and were therefore less likely to seek assistance, putting them at greater risk of harm (Lehmann et al. 2010). Carers and general practitioners of people WDLA were also less likely to detect their condition, which often went unnoticed until a major crisis occurred (Gould et al. 2010; Lehmann et al. 2010; Sibley et al. 2002; Soniat 2004; Wilkins et al. 2007). Because of these safety concerns, various authors reported that carers and healthcare professionals were often pressured to institutionalise people WDLA (Ebly, Hogan & Rockwood 1999; Freedman 1996; Smith et al. 2007;

Taylor & Donnelly 2006; Tierney, Charles, Snow, et al. 2001; Waugh, F., Napier & Bonner 2004; Yaffe et al. 2002). In fact people WDLA were found to be placed in residential care facilities at disproportionately higher rates than those with similar levels of impairment co-residing, and avoiding risk was likely to be a key reason (Tierney, Charles, Snow, et al. 2001; Waugh, F., Napier & Bonner 2004). Furthermore, placement in residential care facilities often appeared to be based on a perceived need to protect people WDLA rather than on any actual risk of harm (Smith et al. 2007; Taylor & Donnelly 2006; Tierney, Charles, Snow, et al. 2001; Waugh, F., Napier & Bonner 2004). These findings are in keeping with Giddens (1999), a British sociologist, who theorised that society is increasingly preoccupied with risk, and that a discourse around ‘at risk bodies’ shapes clinical and policy responses, particularly with older people, regardless of their physical well-being or actual health status.

In recognising the risk of premature institutionalisation for people WDLA, two prospective studies were conducted to investigate whether it is possible to predict which people WDLA were at highest risk of needing emergency services (Tierney, Charles, Jaglal, et al. 2001; Tierney et al. 2004). Tierney et al. (2001) and Tierney et al. (2004) found 24.6 per cent and 21.6 per cent (respectively) of people WDLA had an incident of harm over an 18 month time period. In these studies, the best predictors of harm were: being male; having self-care deficits; poor performance on the neuropsychological Trial Making Test, Part B (a diagnostic tool used in clinical settings to assess cognitive dysfunction); having fewer social resources; poor performance on the mini-mental state examination (MMSE); presence of chronic obstructive pulmonary disease (COPD) and cerebrovascular disorders. The authors contended that monitoring nutritional intake and providing support with medication compliance can alleviate the risk of malnutrition and medication errors for people WDLA (Tierney, Charles, Jaglal, et al. 2001; Tierney et al.

2004). The risk of harm can therefore be reduced through monitoring and support of others, particularly for those predicted to be at greater risk. The level of available support was found to be an important consideration when assessing risk for people WDLA (Miranda-Castillo, Woods & Orrell 2010). Gilmour's (2004) qualitative study exploring day-to-day risk factors for ten people WDLA identified heating, cooking, falling, getting lost and managing money as the main risks. Consistent with the previous two studies (Tierney, Charles, Jaglal, et al. 2001; Tierney et al. 2004), Gilmour (2004) found that the support of family carers, neighbours, health and social services and members of the local community helped to manage and alleviate risks, which in turn enabled people WDLA to remain living at home for longer.

Although these studies make valuable contributions to understanding the risks of living alone with dementia, they failed to examine the relationship between risk and the stage of dementia and how this may affect the ability of the person WDLA to remain living at home (Nourhashemi et al. 2005). A further limitation of these studies was that they only addressed physical risks and failed to consider emotional or social risks from the perspective of the person WDLA, such as exclusion from the decision-making process (Harris 2006; Nourhashemi et al. 2005). One explanation for an emphasis on physical risk may rest with researchers' interpretation and understanding of risk, as Clarke (2000) discovered that the construction of risk is very different between healthcare professionals and people with dementia, and this may also be true for researchers.

Clarke (2000) found that the key concern for healthcare professionals was the safety of the client, while the main concern for people with dementia was the maintenance of self-identity and interpersonal relationships. Clarke (2000) reported that these differences may cause conflict between healthcare professionals and the person with dementia. Consistent with these findings, an Australian online survey completed by 101 case managers

supporting people with dementia living in the community, found that the main priority for case managers was the safety and physical well-being of the client (Sait 2013), while a significant concern for case managers in managing risk was determining when the level of risk was too great for clients to remain at home (Sait 2013). In fact, the findings from two UK studies, a survey of 46 service managers from health, social and voluntary sector organisations and the conducting of five collaborative learning groups with healthcare practitioners, found that managing risk in dementia care was extremely complex (Clarke, CL et al. 2009; Clarke, CL et al. 2011). Contributing to this complexity was the wide variation in understanding of risks among healthcare professionals and the many factors influencing perceptions of risk, such as the views of family carers, availability of service resources and professional and organisational culture (Clarke, CL et al. 2009; Clarke, CL et al. 2011). Clarke et al. (2009) highlighted the importance of multi-disciplinary teams working together to develop a shared understanding of the risks for persons with dementia and to agree on the actions taken to reduce risks.

In 2010, the UK Department of Health published a risk guidance document for use across health and social care systems aimed at providing a common approach to risk for people with dementia living in the community (Manthorpe & Moriarty 2010). Manthorpe and Moriarty (2010) found that one of the biggest barriers to the autonomy of people with dementia was an overly cautious approach to risk by healthcare professionals. Clarke et al. (2011) similarly found that the complexity of risk management can lead to an emphasis on physical safety and that underpinning this risk-averse approach was fear of harm to the person with dementia and the risk of a complaint or legal action. Manthorpe and Moriarty (2010) recommended changing the way risk is perceived by developing systems which support and manage risk and suggested renaming it 'risk enablement' (Manthorpe & Moriarty 2010). Clarke et al. (2011) also recommended that healthcare professionals and

their organisations review their cultural contexts and the extent to which physical risk is privileged over psychological risk; although, the authors acknowledged that the mechanisms for assessing physical risks were more established than those for psychological risks (Clarke, CL et al. 2011). Manthorpe and Moriarty (2010) suggested that a tailored approach for each person should be taken which focuses on the person's current capabilities rather than on their functional losses, thereby promoting the agency of the person with dementia. Clarke et al. (2011) also proposed incorporating the life story of the person with dementia into the assessment of risk and highlighted the importance of ensuring effective advocacy of the views of the person with dementia. This research recognised the importance of the person with dementia and their agency in enabling risk, yet no further research on agency or risk enablement tools was identified.

Needs of people WDLA

As previously discussed, from 2005 onwards the predominant theme in the literature with respect to people WDLA changed from concerns over their safety to assessment of their needs. This review identified three quantitative studies and one report relevant to this topic (Gould et al. 2010; Meaney, Croke & Kirby 2005; Miranda-Castillo, Woods & Orrell 2010; Van der Roest et al. 2009). Two of these studies showed that people WDLA had more unmet needs than those co-residing (Meaney, Croke & Kirby 2005; Miranda-Castillo, Woods & Orrell 2010), while a further study showed that people with dementia reported fewer needs than their carers (Van der Roest et al. 2009). Despite differences in themes, the needs of people WDLA almost mirrored the key risks to people WDLA highlighted in the previous section and discussed further below (Meaney, Croke & Kirby 2005; Miranda-Castillo, Woods & Orrell 2010; Van der Roest et al. 2009). Consistent with Gilmour's (2004) study, Meaney, Croke and Kirby (2005) also found that the

majority of assessed needs of people WDLA can be addressed by increased support from community services.

The needs of people WDLA compared to those co-residing were assessed in two studies using different tools, with the care needs assessment pack for dementia (CareNap-D) used in an earlier study (Meaney, Croke & Kirby 2005) and the Camberwell Assessment of Needs for the Elderly (CANE) tool used in the more recent study (Miranda-Castillo, Woods & Orrell 2010). Although the use of different tools made direct comparison difficult, some commonalities existed; both studies found people WDLA had more unmet needs than those co-residing, particularly in the domains of memory, home, food, medication compliance, self-care, accidental self-harm and managing finances (Meaney, Croke & Kirby 2005; Miranda-Castillo, Woods & Orrell 2010).

Similarly, Van der Roest et al. (2009), who assessed the needs of community-dwelling people with dementia from the perspective of the person and their informal carer, found that the most frequent areas where assistance was required included food, finances, memory and household activities (Van der Roest et al. 2009). However, in this study the majority of needs in these domains were considered to be met, with the exception of memory support (Van der Roest et al. 2009). In contrast, unmet needs were reported by people with dementia in the domains of information, psychological distress and company, while carers reported additional unmet needs in areas such as daytime activities, eyesight and hearing (Van der Roest et al. 2009). Van der Roest (2009) found that the type and severity of dementia, living situation and carer characteristics affected the number of reported needs, which may explain the differences in results across the studies. These factors along with the level of support available are therefore important aspects to consider when assessing the needs of a person with dementia.

Van der Roest et al. (2009) also found that people with dementia reported fewer needs than their informal carers and that agreement between them was low, particularly in relation to risk of harm or abuse. The authors suggested that these differences may be influenced by the level of carer-burden and the coping mechanisms of people with dementia. Another reason postulated by the authors was that people with dementia underreported their needs for fear of losing autonomy. Further qualitative research may provide greater understanding of these findings from the perspective of the person with dementia and their carer.

In 2010, the United States Administration on Aging reported on the provision of services for people with dementia who live alone, informed by interviews conducted with people WDLA to identify their needs (Gould et al. 2010). No details were provided on the number of people interviewed or the level of support available, however those interviewed said they would like to have someone in their home to assist them with managing finances, reminding them of appointments, checking their mail and advocating for them (Gould et al. 2010). Desire for support with memory and finances was consistent with previous studies, but assistance with mail and support of an advocate had not been identified in other studies (Meaney, Croke & Kirby 2005; Miranda-Castillo, Woods & Orrell 2010; Van der Roest et al. 2009). Although people WDLA expressed a wish for an advocate, no further information was provided on the reasons for this or the perceived benefits of advocacy involvement. Further qualitative research is required to elucidate the alleged need for an advocate in supporting people WDLA.

Experiences of people WDLA

More recently, it has been recognised that listening to the experiences of the person with dementia is important in improving health services and in promoting social inclusion (Pesonen, Remes & Isola 2011). This recognition has led to a significant increase in the

number of studies incorporating the perspectives of people with dementia (De Boer et al. 2007; Pesonen, Remes & Isola 2011; Sabat 1998). However, the same interest has not been shown in research incorporating people WDLA. Only five qualitative studies presented in six publications exclusively exploring the experiences of people WDLA (De Witt, Ploeg & Black 2009, 2010; Duane, Brasher & Koch 2013; Frazer, Oyeboode & Cleary 2012; Harris 2006; Sait 2013) were identified, and merely a further four qualitative studies incorporating the experiences of people WDLA were found (Caddell & Clare 2011; Parsons-Suhl et al. 2008; Preston, Marshall & Bucks 2007; Steeman et al. 2007).

Although this body of research considered the experiences of living with dementia, each of the studies focused on different aspects such as coping (Duane, Brasher & Koch 2013; Frazer, Oyeboode & Cleary 2012; Harris 2006; Preston, Marshall & Bucks 2007; Sait 2013), identity (Caddell & Clare 2011), and the meaning of living with dementia/memory loss (De Witt, Ploeg & Black 2009, 2010; Parsons-Suhl et al. 2008; Steeman et al. 2007). A brief overview of each study is provided in Table 2, below.

Table 2: Summary of the literature on the experiences of people WDLA

Authors (Year)	Location of study	Number of participants	Age range	Methodology	Major research focus
Sait (2013)	Australia	6 living alone (5 females, 1 male)	74-92 years	Thematic analysis	coping
Duane, Brasher & Koch (2013)	Australia	19 living alone (13 females, 6 males)	69-91 years	Content analysis	coping
Frazer, Oyeboode & Cleary (2012)	UK	8 females living alone	75-95 years	Interpretative phenomenological analysis	coping
De Witt, Ploeg & Black (2009, 2010)	Canada	8 females living alone	58-87 years	Interpretative phenomenological analysis	meaning
Harris (2006)	USA	15 living alone (13 females, 2 males)	60-87 years	Grounded theory	coping
Preston, Marshall & Bucks (2007)	UK	12 (5 female and 7 male) 2 living alone	58-81 years	Interpretative phenomenological analysis	coping
Caddell & Clare (2011)	UK	10 (5 female, 5 male) 2 living alone	65-88 years	Interpretative phenomenological analysis	identity
Parsons-Suhl et al. (2008)	Canada	12 (9 female, 3 male) 1 living alone	59-83 years	Hermeneutical Phenomenological	meaning
Steeman et al. (2007)	Belgium	20 (16 female, 4 male) Living arrangement not defined	69-91 years	Grounded theory	meaning

In addition, two comprehensive literature reviews examining the perspectives of people with early stage dementia are included in this review due to the broad similarity of findings on the experiences of people with dementia and people WDLA (De Boer et al. 2007; Steeman et al. 2006). De Boer's (2007) review incorporated 50 qualitative and quantitative studies, while Steeman et al. (2006) restricted their review to qualitative

studies, of which they deemed 33 to be relevant. A longitudinal study, conducted by Macquarrie (2005) on the experiences of Alzheimer's disease (AD), also referenced by De Boer et al (2007), was deemed relevant to this review as it was the only study identified which specifically made reference to agency of people with dementia.

Many of these studies reported that the majority of people with dementia have an awareness of their condition (Caddell & Clare 2011; De Boer et al. 2007; Parsons-Suhl et al. 2008; Preston, Marshall & Bucks 2007; Steeman et al. 2007) and three common themes of their experiences emerged from the literature which were: independence and control; social withdrawal; and coping strategies. These three themes are further discussed below.

Independence and control

A particularly dominant theme was independence and control; studies indicated that people WDLA valued both highly and it was extremely important to them to be able to do things for themselves and make their own decisions for as long as possible (Duane, Brasher & Koch 2013; Frazer, Oyeboode & Cleary 2012; Harris 2006; Sait 2013). Achieving whatever they still can provided a sense of satisfaction and helped sustain a sense of worth (Duane, Brasher & Koch 2013; Harris 2006; Sait 2013). While people WDLA accepted a level of support was required they wanted to ensure support was only provided when necessary (Duane, Brasher & Koch 2013; Harris 2006; Sait 2013). For some people WDLA, loss of control and loss of ability to act led to feelings of incompetence and diminished self-esteem (Steeman et al. 2006) which resulted in a sense that the world was devoid of meaning (De Boer et al. 2007; Parsons-Suhl et al. 2008; Steeman et al. 2006). Losing independence and control is a consequence of dementia which often affects many aspects of life, such as the ability to act, but despite this no studies were identified which specifically explored the agency of people WDLA.

Two significant threats to the independence and control of people WDLA were highlighted in the literature which were: losing the ability to drive; and future decline in cognitive function. Losing the ability to drive was particularly significant for people WDLA as it increased their dependency on others (De Witt, Ploeg & Black 2009; Frazer, Oyeboode & Cleary 2012; Harris 2006; Sait 2013), reduced their ability to participate in social activities (Frazer, Oyeboode & Cleary 2012) and decreased their overall sense of freedom (Frazer, Oyeboode & Cleary 2012), which generated feelings of being ‘closed in’ (De Witt, Ploeg & Black 2009, p. 277).

Future decline was also a major concern for people with dementia as it was associated with an increased dependency on others (De Witt, Ploeg & Black 2009; Harris 2006; Steeman et al. 2006) and ‘a doomed future’ (Steeman et al. 2006). For some people WDLA, future decline was feared more than death, which often culminated in thoughts of suicide or the wish for death before further progression of the illness (De Witt, Ploeg & Black 2009, 2010). Although these studies explored threats to the loss of independence and control and the negative outcomes associated with these losses, a clear gap in the literature is the lack of studies which explore factors that may enhance independence and control for people WDLA.

Social withdrawal

Social withdrawal of people with dementia was a recurring theme in the literature; a major factor contributing to their withdrawal was a loss in self-esteem (De Witt, Ploeg & Black 2009; Duane, Brasher & Koch 2013; Harris 2006). Caddell and Clare (2011) found that a person’s identity was demonstrated through their actions and activities and the loss of this identity can lead to a diminished sense of self. As people with dementia lose the ability to perform certain tasks they can begin to feel worthless because they can no longer be relied upon, which invokes feelings of detachment from their community, in

turn leading to social withdrawal (De Witt, Ploeg & Black 2010; Duane, Brasher & Koch 2013; Parsons-Suhl et al. 2008). Steeman (2006) found that the self-esteem of people with dementia can also come under threat from being accused, restricted, ignored or patronised by others, and in an effort to maintain a sense of self-worth, many people with dementia actively choose to withdraw from interactions with others (De Witt, Ploeg & Black 2009; Duane, Brasher & Koch 2013; Harris 2006; Macquarrie 2005).

Various authors have described the tension people with dementia face between wanting to be themselves and wanting to display a more socially capable self, concealing their diagnosis and symptoms from others in order to protect themselves from judgement (De Boer et al. 2007; De Witt, Ploeg & Black 2009; Frazer, Oyeboode & Cleary 2012; Steeman et al. 2006). These studies showed that for people with dementia the loss in cognitive function, and the actions of others, can lead to a reduction in self-esteem which in turn can contribute to their social withdrawal. This withdrawal is of potential concern as people with dementia who have fewer social resources were reported to be at greater risk of harm (Tierney et al. 2004).

In addition, memory loss for people with dementia can result in feelings of shame, fear of being exploited and fear of getting lost, which was found to significantly constrain the social interactions of these individuals (Frazer, Oyeboode & Cleary 2012). Feelings of shame and a sense of vulnerability led people WDLA to retreat to the safety of their homes (Frazer, Oyeboode & Cleary 2012; Harris 2006). People WDLA felt comfortable and safe from the exploitation of others in their own home (Duane, Brasher & Koch 2013; Frazer, Oyeboode & Cleary 2012; Harris 2006), with the home acting as a safety barrier from the outside world (De Witt, Ploeg & Black 2010). People WDLA were aware there were safety risks involved with living at home but they were not concerned by them (Duane, Brasher & Koch 2013; Harris 2006). These studies suggest that the home is

particularly significant for people WDLA as it provides a place of sanctuary and protection against the outside world.

Coping mechanisms

Despite its impact, the majority of people with dementia did not undergo it passively, but instead actively adopted numerous coping strategies to deal with its challenges (De Boer et al. 2007; Preston, Marshall & Bucks 2007). Steeman et al. (2007) suggested that people with dementia face constant tension between trying to maintain or protect their previous way of living while at the same time employing strategies to adjust to the impact of dementia. Authors have used different terms to describe this tension such as: 'continuity and change' (Caddell & Clare 2011), '*acceptance and fighting it*' (De Boer et al. 2007; Preston, Marshall & Bucks 2007), '*being valued to being worthless*' (Steeman et al. 2007), '*self-protection and self-adjustment*' (Steeman et al. 2006), and '*agency and objectification*' (Macquarrie 2005). While the terms used to describe this tension may differ, the coping strategies identified were broadly similar, and for the purpose of the review they are presented under self-protection and self-adjustment strategies.

Examples of self-protection strategies identified include: minimisation and normalisation (De Boer et al. 2007; Steeman et al. 2007); downgrading of expectations (De Boer et al. 2007; Frazer, Oyeboode & Cleary 2012; Preston, Marshall & Bucks 2007); acceptance (Frazer, Oyeboode & Cleary 2012); use of humour (De Boer et al. 2007; Frazer, Oyeboode & Cleary 2012; Parsons-Suhl et al. 2008; Preston, Marshall & Bucks 2007); avoidance of thinking or talking about problems or the future (De Boer et al. 2007; Preston, Marshall & Bucks 2007) and confronting difficulties only when necessary (Caddell & Clare 2011). De Witt, Ploeg and Black (2009) found that people WDLA attempted to 'hold back' the dreaded future in order to protect themselves from negative thoughts and thus tended to live one day at a time (Caddell & Clare 2011; De Boer et al. 2007).

Denial or avoidance of the term 'dementia' was also identified as a coping strategy, which stemmed from a fear that admitting that dementia will lead to a loss of independence and control (De Boer et al. 2007; Harris 2006; Macquarrie 2005; Steeman et al. 2006).

Macquarrie (2005) argued that denial by the person with dementia was a form of resistance and it represented an attempt by the person to hold on to their agency.

Consistently, these studies showed that whilst people with dementia were losing agency, they were also exerting agency in various ways to protect themselves and their previous way of living.

Many self-adjustment strategies identified relate to coping with memory loss (Harris 2006; Sait 2013) such as using memory aids (Frazer, Oyeboode & Cleary 2012; Parsons-Suhl et al. 2008; Preston, Marshall & Bucks 2007; Steeman et al. 2006), conducting memory improvement exercises (Frazer, Oyeboode & Cleary 2012), using assistive technology (Harris 2006) and establishing daily routines and systems (De Boer et al. 2007; Harris 2006). Further examples of self-adjustment strategies included: keeping busy in meaningful activities (De Boer et al. 2007; Harris 2006); reliance on medication (De Boer et al. 2007); participating in support groups (Steeman et al. 2006); and emphasis on past and present competencies (Duane, Brasher & Koch 2013; Frazer, Oyeboode & Cleary 2012; Harris 2006; Macquarrie 2005; Steeman et al. 2006; Steeman et al. 2007).

Macquarrie (2005) was of the opinion that reminiscing about one's competent self is an important means by which people with dementia fight against the loss of agency, while staying active and engaged provided people with dementia with a sense of pride and meaning over their present life. In stark contrast to family members, people with dementia tended to focus on existing capabilities rather than on their losses, particularly when interacting with others (De Boer et al. 2007; Duane, Brasher & Koch 2013; Steeman et al. 2007). These strategies helped people with dementia cope with the loss of cognitive

function and remain positive about their present lives (De Boer et al. 2007; Steeman et al. 2007). Although these studies showed that people with dementia can exert agency and implement a wide range of strategies to adapt to their condition, it is also known that some people with dementia struggle to adapt, predisposing them to depression (De Boer et al. 2007; Steeman et al. 2006). A limitation of all of these studies was that they failed to explore why some people with dementia can adjust successfully to the challenges of dementia while others cannot.

Review of advocacy literature

As previously mentioned, the number of studies on dementia advocacy is extremely limited (Cantley & Steven 2004; Dunning 2005; Gorczynska 2007). Therefore, the scope of this review was expanded to include advocacy for older persons, and advocacy for older people with mental health issues. A total of 79 documents were identified but only 18 publications were included in this review, as documents which provided only descriptive examples of advocacy schemes were excluded. The 18 published documents identified included nine papers, seven reports, one book and one book chapter, dealing with practice-based knowledge and sharing the perspectives of advocates and service users on advocacy services. The majority of these studies (of which there were eight) provided practice-based knowledge on dementia advocacy (Killeen 1996; Wells 2006, 2007), older persons advocacy (Dunning 2005; Scourfield 2007), mental health advocacy (Wetherell & Wetherell 2008), and Independent Mental Capacity Advocate Services (IMCA) (Gorczynska 2007; Mapes 2009). A further six studies explored the perspectives of advocates and/or healthcare professionals (Atkinson 1999; Cantley & Steven 2004; Cantley, Steven & Smith 2003; Jones 2004; Luke et al. 2008; Redley et al. 2009). Of these six studies, only one specifically explored dementia advocacy from the perspective of advocates (Cantley & Steven 2004; Cantley, Steven & Smith 2003).

Although this research provided valuable insight into dementia advocacy, a significant limitation was the absence of the perspective of the service user. In fact, only four of the eighteen studies included the perspectives of the (aged-care or mental health) service user, with none of these studies specifically exploring the perspective of the user of dementia advocacy (Brown & Standen 2011; Forbat & Atkinson 2005; Margiotta et al. 2003; Wright 2006). Therefore, a significant gap in the literature was the perspective of the person with dementia. Acknowledging this gap, Cantley and Steven (2004) called for further research on dementia advocacy incorporating the perspectives of the service user, their families and other service providers.

Notwithstanding the limitations of these eighteen documents, three common themes relevant to this thesis were identified: the benefits of advocacy; the barriers to advocacy; and the complexity of dementia advocacy. The findings in relation to each of these themes are discussed in more detail below.

Benefits of advocacy

Four studies addressing the benefits of advocacy were identified; two of these studies explored the benefits for service users (Brown & Standen 2011; Wright 2006), and two explored the benefits for service providers (Jones 2004; Margiotta et al. 2003). Advocate involvement was found to provide both physical and emotional gains for service users, with physical gains associated with tangible outcomes such as access to services, while emotional gains were associated with improvements in emotional well-being (Brown & Standen 2011; Wright 2006). Atkinson (1999) and Dunning (2005) also referred to these physical and emotional benefits of advocacy for older people in their respective reviews. The benefits for service providers included: increases in time saving; improvements in service user understanding; and greater protection for service providers (Jones 2004; Margiotta et al. 2003). These benefits are discussed in more detail below.

Service user benefits

A wide range of motives for using advocacy services with older people were identified, which included: protection from abuse or discrimination; access to services; and the protection of rights, including the right to be heard (Wright 2006). Wright (2006) conducted qualitative interviews with 35 older people who had used advocacy services, to explore the use and benefits of advocacy involvement. Advocacy was viewed favourably by all participants and positive outcomes, classified as either physical or emotional gains, were experienced (Wright 2006). Examples of physical gains included access to services and improvements in financial circumstances through improved access entitlements (Wright 2006), while examples of emotional gains included increases in feelings of self-confidence and self-esteem (Wright 2006).

These findings were consistent with the perspectives of advocates, who reported in other studies that clients valued having an advocate to talk to, who will listen to them and can help them express their views (Forbat & Atkinson 2005; Jones 2004). In addition, Wetherell and Wetherell (2008), based on their experience as advocates, were of the view that clients who are encouraged and empowered by their interaction experience a much greater improvement in quality of life. Advocacy involvement was therefore shown to provide both physical and emotional benefits for older people.

In contrast, people with mental health problems only identified physical benefits associated with advocacy involvement (Brown & Standen 2011). Brown and Standen (2011) conducted a quantitative study to explore advocacy needs in which questionnaires were completed by older people with mental health problems, their carers and service providers across nine organisations. A limitation of this study was that people with mental health problems participating in the study had no experience of advocacy. In spite of this, benefits were perceived: during appointments or treatment (78%); when accessing

information (70%); and when making a complaint (63%). Advocacy was also perceived to be beneficial during care-review assessments and care planning or when accessing healthcare services (Brown & Standen 2011).

The lack of emotional gains highlighted in Brown and Standen's (2011) study may be due to differences in the needs of older people compared to older people with mental health issues, while it may also relate to the experiences of service users who have used advocacy services compared to those who have not. A further explanation may be differences in methodology between the two studies as a quantitative approach may influence participants to focus more on tangible or physical gains. The lack of reports of emotional gains may also be influenced by the questions asked in the questionnaire, but the questions themselves were not provided in either article, making further interpretation difficult. Despite this, both Brown and Standen (2011) and Wright (2006) have shown that advocacy involvement has the potential to provide a wide range of benefits for service users, although these benefits may differ across the different service user groups. It is therefore not possible to determine the actual benefits of advocacy involvement for people WDLA without conducting a specific study on this subject. The perceived benefits of advocacy involvement may also differ amongst service users and service providers. For example, Brown and Standen (2011) found that 44 per cent of people with mental health problems, compared to 64.5 per cent of service providers, perceived advocacy to be beneficial for accessing health and/or social care services. Brown and Standen's (2011) study highlights the importance of examining multiple perspectives to clearly understand the perceived benefits of advocacy.

Furthermore, Brown and Standen (2011) found that service providers and some carers did not believe advocacy to be beneficial to people with a cognitive impairment. No further information was provided to explain this phenomenon other than a suggestion that there

was a lack of understanding of the ways in which advocacy can benefit these people. This perception may negatively influence referral of clients to the advocacy service; however, it is unclear whether these service providers or carers were in fact providing services to people with dementia. This finding further demonstrates the need for more research on advocacy for people with dementia from multiple perspectives as the opinions of service users, service providers and carers can significantly influence the understanding of advocacy and its use.

Service provider benefits

Advocacy was shown to benefit service providers of older person's in three ways: delivering time savings; providing a safety net; and improving staff understanding of service users (Jones 2004). In interviews with 24 service providers aimed at investigating service provider benefits, advocates were found to help progress cases in circumstances where either limited service resources were available or where significant service user communication deficits existed (Jones 2004). This assistance led to time saving for the service providers. Provision of training by advocates to service providers on the needs of older people was also reported to lead to improvements in the understanding of their clients (Jones 2004). Being able to refer clients to an independent advocacy organisation also provided service providers with reassurance and a level of protection in circumstances where conflict between the service user and service provider had arisen (Jones 2004).

In their literature review of older person's advocacy, Margiotta et al. (2003) similarly identified benefits for the service provider from referring to an independent organisation. These providers sometimes faced the dilemma of representing the service users' needs against the needs or requirements of their organisation, and the availability of independent advocacy services ensured staff did not have to take on this conflicted role (Margiotta et

al. 2003). Although numerous benefits to service providers from advocacy involvement with older persons were highlighted, it is unclear whether these same benefits are experienced by service providers working in other areas, such as dementia.

Barriers to advocacy

Brown & Standen (2011) found that although a significant proportion (88%) of service providers believed advocacy would be beneficial to some extent, less than a quarter of service providers had previously referred clients to an advocacy service. Three main reasons contributed to the lack of referrals: difficulties in the referral relationship between health professionals and advocates; lack of awareness or understanding of advocacy; and lack of availability of advocacy services (Brown & Standen 2011; Cantley, Steven & Smith 2003; Dunning 2005; Forbat & Atkinson 2005; Killeen 1996). These issues are discussed further below.

As the legal status of advocacy is ambiguous, advocates predominantly rely on healthcare professionals to refer clients to the advocacy service (Killeen 1996). Consequently, good relationships between advocates and healthcare professionals are critical to an advocacy service's success (Cantley, Steven & Smith 2003; Killeen 1996). However, establishing good relationships can prove difficult as the role of an advocate and a healthcare professional can differ and may often be at odds with each other (Cantley, Steven & Smith 2003; Forbat & Atkinson 2005; Wetherell & Wetherell 2008). The advocate role is to represent the wishes of the person, which may often conflict with what healthcare professionals believe is in the best interests of that person (Cantley, Steven & Smith 2003; Forbat & Atkinson 2005; Wetherell & Wetherell 2008). The circumstances surrounding advocate referral can also influence the relationship between healthcare professionals and advocates. Killeen (1996) and Cantley, Steven and Smith (2003) found that advocacy involvement was often only considered as a 'last resort' or in circumstances where

conflict between the service provider and service user had occurred (Cantley, Steven & Smith 2003; Killeen 1996). These circumstances were found to exacerbate relationship tensions as often a decision was urgent and pressure was placed on the advocate to resolve the issue quickly (Cantley, Steven & Smith 2003; Killeen 1996).

Furthermore, many healthcare professionals, particularly nurses and social workers, believe that their role includes patient advocacy and do not perceive a need for independent advocates (Forbat & Atkinson 2005; Margiotta et al. 2003). Various authors found that these healthcare professionals may attempt to undermine advocacy, be resistant to advocacy involvement or restrict access to clients (Luke et al. 2008; Margiotta et al. 2003). This advocate ambivalence was found to be more pronounced in acute care settings where clinicians and medical staff appeared sceptical over the benefit of advocacy in medical decisions and believed that advocacy involvement only added undue complexity and elongated the time a client remained in hospital (Gorczyńska 2007; Luke et al. 2008). Therefore, poor relationships between healthcare professionals and advocates and a lack of differentiation between roles have the potential to result in low numbers of client referrals to the advocacy service.

Lack of awareness and understanding of the benefits of advocacy amongst healthcare professionals and service users has been emphasised as a major barrier by a number of researchers (Atkinson 1999; Brown & Standen 2011; Dunning 2005; Forbat & Atkinson 2005; Margiotta et al. 2003; Scourfield 2007; Wetherell & Wetherell 2008). Forbat and Atkinson (2005) were of the view that healthcare professionals require greater clarity on the aims of independent advocates and an appreciation of the difficulties advocates face in questioning either an established system or an organisation from an outsider's position. Various authors consider there to be a need to provide education to healthcare professionals and service users on the advocacy role, as a shared understanding is critical

to establishing and maintaining an effective advocacy service (Atkinson 1999; Brown & Standen 2011; Margiotta et al. 2003; Wetherell & Wetherell 2008). It is unclear whether there is the same need to provide this education in dementia advocacy as these findings relate to older persons and older persons with mental health advocacy.

A further barrier found was that advocacy is not universally available and access is often patchy and dependent upon a range of historical, geographical and financial factors (Margiotta et al. 2003; Scourfield 2007). Finance was a major concern, as funding was found to be precarious for the majority of advocacy organisations; this insecurity has led to the closure of many schemes (Forbat & Atkinson 2005; Manthorpe & Martineau 2010). Atkinson (1999) reported that only through secure funding is it possible to invest more in recruitment, training, supervision and support of advocates, and to develop long term planning. Atkinson (1999) acknowledged that access to advocacy must be greatly improved, and Dunning (2005) contended that there should be a legal right to advocacy, and that local authorities should be compelled to support independent advocacy.

Complexity of Dementia Advocacy

Many authors acknowledged that dementia advocacy is extremely complex and significantly different from other advocacy services due to fluctuations in the capacity of persons with dementia (Dunning 2005; Killeen 1996; Wells 2006, 2007). Despite this, there was a paucity of evidence-based research on the topic, and much of what was available was practice-based guidance to advocates on the challenges of dementia advocacy (Cantley, Steven & Smith 2003; Wells 2006). Three aspects which contributed to the complexity of dementia advocacy identified were: client capacity assessments; provision of non-instructed advocacy; and the relationship between advocate and client. These are discussed further below.

Although assessment of capacity is not part of the formal role of an advocate, dementia advocates frequently have to assess and reassess a client's decision-making capacity (Wells 2006). This assessment must consider the client's capacity to consent to the involvement of an advocate, to understand the problem and the relevant information, to make a decision, to instruct the advocate and to give consent to actions taken on their behalf by the advocate (Cantley & Steven 2004; Cantley, Steven & Smith 2003). Wells (2006) suggested that in the absence of a universal capacity assessment tool, capacity could be assessed either through providing additional information to the client to see if it makes a difference to the client's response or to ask the same question but in a slightly different way. This approach may challenge some advocates and their understanding of advocacy, as the traditional role of the advocate is to be a voice for the client and not to question the wishes or choices of the client (Wells 2006). However, no research was available on how dementia advocates and their organisations addressed the issue of client capacity within their organisations.

The eventual consequence of dementia may be an inability to direct an advocate, in which case the advocacy organisation may choose to provide non-instructed advocacy (Wells 2007). The concept of non-instructed advocacy has led to considerable debate within the advocacy world on whether it is in fact advocacy, and there remains no agreed definition of non-instructed advocacy (Cantley & Steven 2004; Henderson 2007; Wells 2006). Non-instructed advocacy has come into prominence in the UK following the creation of the Independent Mental Capacity Advocate (IMCA) under the *Mental Capacity Act 2005*. Prior to its introduction, seven advocacy organisations participated in a pilot project, under the Department of Health (Redley et al. 2009). In this project, 33 per cent of all clients who received IMCA services suffered from dementia and in more than half of the decisions completed (54 per cent of 109 completed cases) clients with the support of an

advocate were able to provide some indication of their wishes (Redley et al. 2009). This pilot project demonstrated that many people who lack capacity can continue, with the support of an advocate, to express their wishes.

Several different approaches have been developed to account for the variation in the nature and extent of cognitive impairment and to provide a best practice guide for advocates when working with people who cannot instruct (Henderson 2007; Wells 2006). The complexity surrounding non-instructed advocacy can lead organisations to veer away from offering this service to their clients (Cantley & Steven 2004; Henderson 2007). To overcome difficulties in receiving instructions, some dementia advocacy organisations are campaigning for their involvement with people to begin in the early stages of dementia, however this depends on the agreement of those responsible for referring clients (Cantley & Steven 2004). A clear gap in the literature was the views of healthcare professionals on early referrals of people with dementia, which is significant given that advocates rely on these client referrals from healthcare professionals.

Many authors highlight the importance of a clear distinction between advocacy and befriending (Atkinson 1999; Cantley & Steven 2004; Margiotta et al. 2003; Wells 2007; Wright 2006). Yet Cantley and Steven (2004) and Dunning (2005) were of the opinion that this distinction can be difficult to adhere to in dementia advocacy. The advocate often spends considerable time with the person with dementia due to difficulties in ascertaining their wishes, or because people with dementia frequently experience a range of issues and, as a consequence, there is a greater chance of emotional attachment (Wells 2006). Cantley, Steven and Smith (2003) found that there was a risk that this attachment would lead to dependence on the advocate or that the advocate could become emotionally attached and have difficulty ending the relationship. This can be particularly difficult if the person with dementia is socially isolated or the advocate perceives the service

provision to be inadequate (Cantley, Steven & Smith 2003). These authors suggested that one way of overcoming this difficulty was to ensure plans for intervention from the beginning also included plans for withdrawal of the service (Cantley, Steven & Smith 2003). However, there was no information in the literature on how advocates achieve this in practice.

An additional risk in this relationship is the power advocates possess to influence their clients. Cantley, Steven and Smith (2003) found that although dementia advocates generally perceived their role to be representing the wishes of their clients, in practice this was not always strictly adhered to. Some advocates, even with the best of intentions, attempted to influence the person with dementia if they thought it might help the person achieve their long term objectives (Cantley, Steven & Smith 2003). Wells (2006), also, was of the view that the advocate role was to assist people with dementia, who may lack insight, to understand the reality of their circumstances and to not let them hope for something unachievable. In both contexts, there are risks in departing from a strictly traditional advocacy role as advocates may misrepresent the wishes of the person with dementia or may unintentionally exert undue influence (Cantley, Steven & Smith 2003). In order to minimise relationship risks, Cantley, Steven and Smith (2003) recommended that advocacy organisations have clear policies in place defining the boundaries of the relationship, and that advocates should constantly reflect on these boundaries in practice.

Overcoming complexities in dementia advocacy

As previously discussed, there is a lack of evidence-based research and established guidelines on dementia advocacy, causing advocates to draw on their own beliefs on whether or not to work with a client and how best to do so (Cantley & Steven 2004; Wells 2006). Dementia advocates also often work in isolation and in potentially hostile environments, which can be very stressful (Cantley, Steven & Smith 2003; Forbat &

Atkinson 2005; Wells 2007). In the absence of guidelines, many authors have stressed the importance of advocacy organisations having appropriate codes of conduct, educational training programs, and supervision and support arrangements to ensure proper practice (Atkinson 1999; Cantley, Steven & Smith 2003; Dunning 2005; Forbat & Atkinson 2005; Margiotta et al. 2003; Scourfield 2007). Wetherell and Wetherell (2008) were of the opinion that poor support and supervision in advocacy leads to problems for both the organisation and the client.

The need for quality standards in advocacy, not specific to dementia, has caused considerable debate. Some advocates were of the view that standards might diminish the core principles, values and spirit of advocacy, while others believed there would be a number of benefits in the development of standards (Dunning 2005; Henderson & Pochin 2001). Dunning (2005) was of the opinion that standards can lead to: harmonised measures to evaluate service effectiveness; accountability, awareness and transparency of the service; safeguards for the client, the advocate and the service; and greater understanding and expectations of the advocacy service. The UK was one of the first countries to implement initiatives aimed at establishing advocacy quality standards and, since September 2008, a national advocacy qualification and an advocacy quality performance mark (QPM) have been introduced (Mapes 2009).

Similarly, in Australia there have been significant advancements in the implementation of advocacy quality standards for the disability sector. In 2011 the Australian Parliament passed amendments to the *Disability Services Act 1986*, to mandate the introduction of a new, independent, third-party quality assurance (QA) system for advocacy agencies funded under the National Disability Advocacy Program (NDAP) (Dept of FaHCSIA 2012). A key feature of the system, which commenced on 1st July 2012, is the development of a set of disability advocacy standards and key performance indicators

(KPIs) against which advocacy organisations must be certified as a condition of future funding (Dept of FaHCSIA 2012). Dementia advocacy is provided through older person's advocacy services and consequently there is a risk that dementia advocacy organisations may not fall under this new quality assurance system. The success of these quality standards in advocacy has yet to be evaluated over time. Furthermore, a concern with these current standards is that they do not specifically address the complexities associated with dementia advocacy, as discussed above in this literature review.

Conclusion

This literature review demonstrated that people with mild to moderate dementia can have the ability to participate in the decision-making process but, despite this, that they have frequently been denied this opportunity by others (Feinberg & Whitlatch 2001; Horton-Deutsch, Twigg & Evans 2007; Tyrrell, Genin & Myslinksi 2006). A significant gap in the decision-making literature was the absence of information on people WDLA, particularly given that they are more marginalised in the decision-making process (Samsi & Manthorpe 2013; Webber, Fox & Burnette 1994). In addition, research has tended to focus on capacity and the meaning of participation for people with dementia but has failed to examine the person's response to exclusion, or the factors which may facilitate or hinder their participation in the decision-making process. One study was found which explored whether healthcare professionals facilitate participation, using social constructionism and critical realism as an appropriate method (Brannelly 2011). However, a significant limitation of this study was that the perspectives of people with dementia and of healthcare professionals was absent given that it was an observational study only.

The review also highlighted that people WDLA faced significant safety risks and unmet needs, and pressure is often placed on those around them to institutionalise them (Waugh,

F., Napier & Bonner 2004). In addition, people with dementia reported fewer needs than their carers, while the construction of risk between people with dementia and healthcare professionals was also found to vary significantly (Clarke, C 2000; Van der Roest et al. 2009).

There is a clear gap however in the literature on our understanding of the way people WDLA view their quality of life and the risks and needs associated with it. Additionally, most recent research exploring the experiences of people WDLA showed that holding on to independence and control was extremely important to this population, yet no studies were identified which explored the impact of the loss of independence and control on people WDLA and on their ability to respond. Moreover, many different coping strategies of people WDLA have been identified but none of the studies explored the reasons why some people were able to adapt successfully to the impact of dementia while others were not. To address the gaps in the literature on people WDLA, this study explores the power of people with dementia living alone to participate in decision-making processes through assessing the impact of dementia on agency and the interactive relationship that exists between structure and agency in shaping the activities of people with dementia living alone.

Many authors have reported that dementia advocacy has played a key role in promoting active participation and supporting social inclusion (Cantley & Steven 2004; Forbat & Atkinson 2005; Goldsmith 1996; Scourfield 2007). However, research to support this claim was extremely limited and much of the data was grey literature. In addition the research which was available was mainly from the perspective of the advocate for the purpose of providing practice-based guidance. A major gap in the literature on dementia advocacy was the perspectives of service users and healthcare professionals. Advocacy for older persons and older persons with mental health issues have demonstrated

numerous benefits, but it was unclear whether those benefits could be translated to dementia advocacy. What is known from the literature is that dementia advocacy is extremely complex and therefore warrants further investigation. A further aim of this study is to explore the features of advocacy which facilitate the participation of people WDLA in the decision-making process.

Chapter 3: Methodology and Methods

Introduction

The overarching aim of this study is to explore the power of people WDLA to participate in decision-making processes with advocacy support. To address this aim the study examined the impact of dementia on agency, the factors influencing agentic action, and the features of an advocacy service that facilitate participation in the decision-making process. The purpose of this chapter is to describe the theoretical framework and the methods used to address the research questions and achieve the overarching study aim. A critical realist paradigm was used to frame the study as it enables theorising from empirical data (Bhaskar 1975). A multi-method and multi-data source qualitative approach was chosen to address the research questions as this facilitates the development of a rich and complex picture of the phenomenon being studied (Liamputtong & Ezzy 2005; Shenton 2004). Danermark's (2002) model of abduction and retroduction was used to analyse the data and guide the researcher in the search for underlying generative mechanisms that may influence agentic power of people WDLA.

This chapter begins by providing a rationale for the study's critical realist framework and the research approach taken. Following this, the qualitative methodology and methods used in the study are discussed, along with the specific issues encountered with each data method and data source. The process of analysis of the data using abduction and retroduction is then presented, before the chapter's conclusion. Steps to ensure rigor have been built into all phases of the research process and are discussed under the relevant sections of this chapter.

Theoretical framework

The research aim was achieved through exploration of the impact of dementia on agency and the interdependent relationship between agency and social structures. The following questions were posed:

- How does dementia impact on the agency of people WDLA?
- What are the factors influencing agentic action of people WDLA?

To examine the ways in which advocacy, as a social structure, can facilitate participation in the decision-making process this specific question was asked:

- What are the features of advocacy that facilitate participation of people WDLA in the decision-making process?

Critical realism was chosen as an appropriate theoretical framework as it offers a stratified meta-theory that focuses on the relationship between social structures and human agency (Angus et al. 2006), which is a focal point of the research questions. It has also been found to be particularly beneficial in the study of health and social inequalities, which is relevant when exploring the power of people WDLA to participate in the decision-making process (Angus et al. 2006). The advantage of critical realism is that it considers agency and structures as separate entities, with their own properties and powers, but acknowledges that each has an effect on the other (Angus et al. 2006; Danermark et al. 2002). As discussed in Chapter One, a person's ability to act not only depends upon their capability (that is, the power of agency) but also upon having the freedom to operate within constraining social structures (that is, agentic power) (Angus et al. 2006; Campbell 2009; Danermark et al. 2002; Wand, White & Patching 2010). In this research, people WDLA are social agents and their power to participate in the decision-making process is

influenced by personal factors (e.g. self-belief, meaning, experience), contextual and structural factors (e.g. cultural norms, health organisations and advocacy services), and the interplay between all of these factors (Sword et al. 2012). People WDLA are often reliant upon social structures, such as health institutions or advocacy services, and these structures can enable or constrain participation in the decision-making process. Therefore, the critical realist exploration of the interplay between agency and social structures is crucial to understanding the factors which influence agentic power of people WDLA (Angus et al. 2006; Archer 2000; Danermark et al. 2002; Wand, White & Patching 2010). In using critical realism, a richer explanatory account is achieved through its focus on the interaction of agency and social structures and the causal mechanisms that underpin participation (Archer 2000; Danermark et al. 2002).

Critical realism is most closely associated with the work of Roy Bhaskar (1975), and was born out of a critique of positivism (Danermark et al. 2002). This criticism predominantly focused on the emphasis given to universal explanations of a phenomenon and the view that research was based only on what could be observed (Clark, Lissel & Davies 2008). Bhaskar (1975) argued that human perceptions or experiences of the world (epistemology) are not tantamount to the world's objective state (ontology) and that the deep dimension of reality means that it cannot be simply reduced to observation of a phenomenon at the empirical (experienced) level (Clark, Lissel & Davies 2008). Bhaskar (1975) argued that social science research should focus on the mechanisms and the properties producing an effect rather than on the event itself. Critical realists consider that to acquire usable knowledge, the mechanisms that produce the empirical events or phenomena, which may or may not be directly visible, must be understood, reflecting a more subjective positioning (Danermark et al. 2002; McEvoy & Richards 2003).

Critical realists propose that ontology (nature of reality) is stratified into three domains: the empirical, the actual and the real (Archer 2000; Bhaskar 1975). The empirical domain consists of what is experienced either directly or indirectly (Sayer 2000). The actual domain is where an event happens in the world, whether it is experienced or not (Sayer 2000). The real domain contains the mechanisms used to produce an event or cause something to happen in the world (Bhaskar 1975). It is this third domain of reality, where generative mechanisms are to be found, that distinguishes critical realism from other forms of realism (Danermark et al. 2002). When activated, these generative mechanisms within the real domain can exert influence over the behaviour of the person WDLA, which may directly or indirectly enable or inhibit participation in the decision-making process.

Generative mechanisms, such as structures, powers and relations, are often not directly observable within the empirical domain but can be experienced indirectly by their ability to cause or make something happen in the world (Danermark et al. 2002; McEvoy & Richards 2003). In exploring the empirical domain, and by theorising on the underlying generative mechanisms, critical realism enables an understanding of the mechanisms that influence the capacity of people WDLA to act independently and exercise choice (Pawson & Tilley 1997). The aim of critical realism is also to answer questions on what works for whom, when and why, and to explore the complex ways in which interventions interact with people and settings to create varied outcomes (Clark, Lissel & Davies 2008; Pawson & Tilley 1997). In this way, the critical realist framework proved beneficial in exploring an advocacy model and examining the ways in which this intervention may work and for whom, when and why, in relation to participation of people WDLA in the decision-making process.

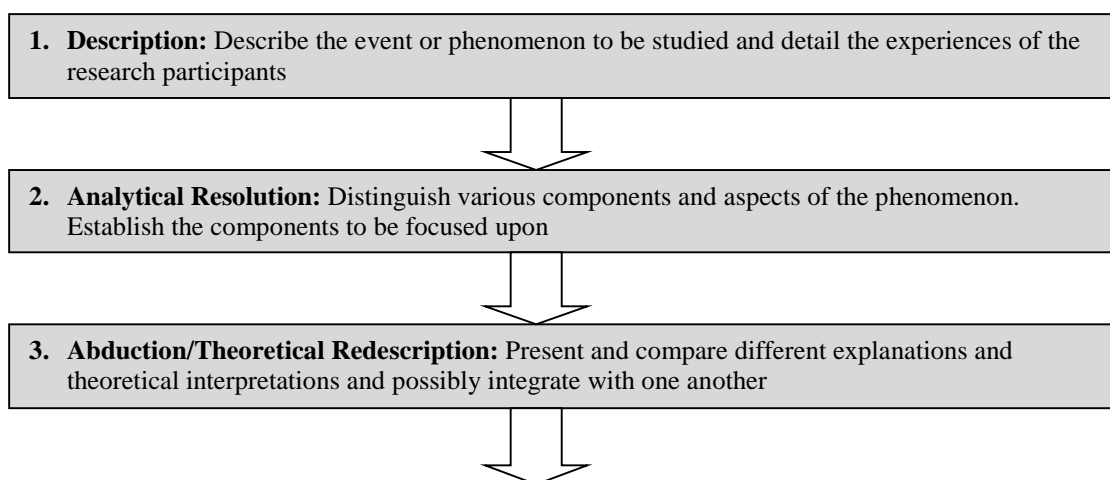
A further advantage of using critical realism is that it views reality as complex and stratified (Danermark et al. 2002). As demonstrated in Chapter Two, most other studies conducted with people WDLA have used a phenomenological or grounded theory methodology. A limitation with both of these methods is that only the empirical domains of reality are explored. Phenomenology is restricted to describing the meaning of an experience for one or more individuals, while grounded theory moves beyond this description to generate a theory based on these experiences (Creswell 2009). Research that is restricted to the empirical domain does not facilitate the identification of the generative mechanisms and the interaction of agency and structural factors which produce the actual event (Danermark et al. 2002). A complex phenomenon, such as participation of people WDLA in decision-making, cannot be fully understood from experiences alone (Birkett 2011). Critical realism however, bridges the gap between the experiences of people WDLA and the actual reality by identifying the mechanisms which influence the power of the person WDLA to participate in the decision-making process.

An additional benefit in using critical realism is that it does not claim objective truth from the experiences of individuals nor does it remove the influence and importance of their interpretations of the world (Clark, Lissel & Davies 2008; Danermark et al. 2002).

Critical realists reject methodological individualism and believe, like positivists, that the truth of an event or phenomenon can be known through exploration of the generative mechanisms causing the event (Denzin & Lincoln 2005). However, unlike positivists, critical realists accept that this truth may be fallible as interpretation is mediated by pre-existing conceptual resources (Archer 2000; McEvoy & Richards 2003). In spite of the potential fallibility of the analysis, which may render generalizable conclusions difficult, research conducted using critical realism, through the development of an explanatory

theory, provides greater knowledge and understanding of the power of people WDLA to participate in the decision-making process.

Critical realism is not without limitations, and one of the difficulties for a novice researcher is that much of the published literature is restricted to theoretical and philosophical debates (McEvoy & Richards 2003). There are relatively few examples of the application of this framework and the strategies used to identify causal mechanisms, although exceptions include Angus et al. (2006), Clark, Lissel & Davies (2008), McEvoy & Richards (2003), and Sword et al. (2012). A further limitation, as referred to in the previous paragraph, is that knowledge of structures is only identified through examination of events and are therefore subjective, as they can be influenced by the researcher's observations of reality (Ackroyd & Fleetwood 2000; Danermark et al. 2002). This means analysis may be fallible (Ackroyd & Fleetwood 2000; Danermark et al. 2002; McEvoy & Richards 2003). To overcome these limitations, and ensure rigor in the analysis of the data, Danermark et al.'s (2002) six step model of abduction and retroduction was used to assist and guide the researcher in the search for underlying generative mechanisms. This process, described below (Figure 2), contributed to the reliability of the study as it ensured the approach to data analysis was consistent across the data sources and data collection methods employed.



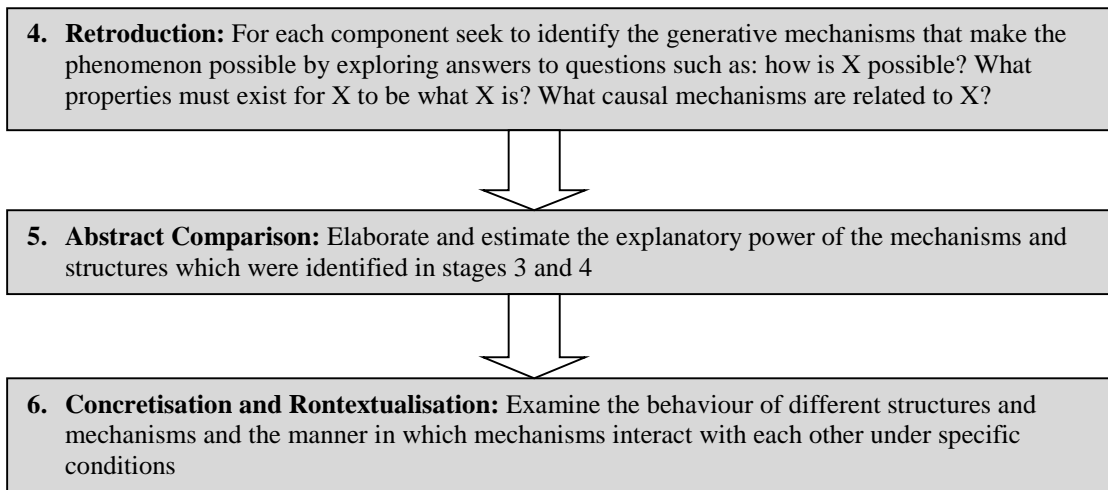


Figure 2: The six stage process of abduction and retroduction (Danermark et al. 2002)

The application of this six stage process of abduction and retroduction is further discussed in the section on data analysis.

Research Approach

There are both legal and moral obligations to consider when conducting ethical research (Creswell 2009). As legally required, before initiation of this study, ethics approval was obtained from the Social Sciences Human Research Ethics Committee of Tasmania. The primary aim of this ethics committee is to protect research participants from any harm associated with their involvement in research (Hansen 2006). Following approval, the study was conducted in line with the Australian National Statement on Ethical Conduct in Human Research (2007) and the parameters established by the ethics board.

Morally, the researcher must be committed to key ethical principles, such as respect for persons, beneficence and justice (Hansen 2006). The particular steps taken to ensure ethical conduct for each respective data source in this study are described under the relevant data source subsection. Protecting participants' identities and ensuring confidentiality was paramount, and measures taken for each participant are discussed under the relevant data source subsection. All data are stored in a locked filing cabinet at

the University of Tasmania and will be stored for a period of five years following publication after which they will be destroyed by secure shredding and erasure methods.

I began this research with no preconceived ideas on the power of people WDLA to participate in the decision-making process. My intention was merely to contribute to the knowledge, and address the gaps identified in the literature, on agency and dementia advocacy. I had not previously worked in the area of dementia, nor had I any personal exposure to the condition. However, after completion of the interviews with people WDLA, it became important to me that their voices were heard, as I had been moved by some of the participants' experiences of marginalisation in the decision-making process. This reaction runs contrary to critical realism; realists seek to uphold universal principles of truth, justice and freedom while maintaining a totally objective stance (Danermark et al. 2002; Guba & Lincoln 2004). Being aware of my position, I employed rigorous methods to ensure that there was no personal bias in analysis of data, which was also an important ethical issue to consider throughout the duration of the study. As previously described, critical realists accept the subjectivity of research findings, as any truth may be fallible as interpretation is mediated by pre-existing conceptual resources (Archer 2000; McEvoy & Richards 2003). The methods taken to ensure truth of the phenomenon included using the six stage process of abduction and retroduction, frequent debriefing with supervisors, peer review, maintaining a reflective diary and external auditing. These measures are discussed further in the data analysis section of this chapter. In addition, my previous role as a trained quality auditor helped me remain critical throughout the research process and assisted me in maintaining a relatively objective stance during analysis despite my concern for the people WDLA.

Qualitative methodology and methods

Critical realism has a methodological and theoretical framework but it is not a method (Clark, Lissel & Davies 2008). Therefore, it does not restrict research to a specific quantitative, qualitative or mixed method approach. The choice of methodology was driven, in this study, by the research questions along with the conceptualisation of the phenomenon under study (Mason 2002; Sayer 2000). Qualitative methodology was chosen as the most appropriate method to meet the study aim as it provides a deeper understanding and explanation of the social phenomenon studied and was a more appropriate data gathering technique for people WDLA (Given 2008; Sayer 1992; Silverman 1997). The research questions focused on the individual agent, their actions and the cultural and social structural factors which affect their agentic power. Acquiring this knowledge required the perspectives of people WDLA and others who have the potential to influence their agentic action (Danermark et al. 2002; Hansen 2006). Quantitative research methods, which emphasise objective measurements, would not facilitate the identification of the specific contextually grounded explanatory mechanisms needed to understand participation of people WDLA in decision-making processes (McEvoy & Richards 2003).

Furthermore, as outlined in Chapter Two, very little research has been conducted on people WDLA and dementia advocacy. Creswell (2009, p. 18) stated that *‘if a phenomenon needs to be understood because little research has been done on it, then it merits a qualitative approach’*. Qualitative methodology has also become increasingly popular in research with cognitively impaired individuals as it essentially involves observing people in their own environment and interacting with them in their own language and on their own terms (Innes 2009; Kirk & Miller 1986). The use of these methods facilitates the involvement of cognitively impaired individuals in research

through recognition of the importance of appropriate communication (Innes 2009).

Therefore, qualitative methodology is appropriate to use in the exploration of the power of people WDLA to participate in decision-making processes.

Critical realists acknowledge the importance, yet potential fallibility, of different perspectives among service users and healthcare professionals and, as a consequence, encourage the use of a variety of data collection methods (Angus et al. 2006). This research used multiple methods of data collection and multiple data sources to ensure an in-depth understanding of the phenomenon under study (Denzin & Lincoln 2005; Liamputtong & Ezzy 2005). The multiple methods consisted of a Quality of Life assessment (QOL-AD), in-depth semi-structured interviews and focus groups. Data sources included: people WDLA who had used the advocacy service in the last six months; dementia advocates; and healthcare professionals involved in the lives of those people WDLA that have also had exposure to the client/advocate interaction. The table below provides details of the data methods used for each data source and the research questions addressed from each data source.

Table 3: Research questions, data sources and data methods

Research Questions	Data Source	Data Methods
1. How does dementia impact on the agency of people WDLA?	People WDLA	. Seven QOL-AD questionnaires . Nine semi-structured interviews
	Advocates	. QOL-AD questionnaires on behalf of seven clients . Four semi-structured interviews
2. What are the factors influencing agentic action of people WDLA?	People WDLA	. Nine semi-structured interviews
	Advocates	. Four semi-structured interviews
	Healthcare Professionals	. Three focus groups . Three semi-structured interview
3. What are the features of advocacy that facilitate participation of people WDLA in decision-making processes?	People WDLA	. Nine semi-structured interviews
	Advocates	. Four semi-structured interviews
	Healthcare Professionals	. Three focus groups . Three semi-structured interview

The use of multiple sources, which is a form of triangulation, assisted the researcher in achieving objective knowledge while also recognising that human experiences are potentially fallible (Mason 2002; Shenton 2004). Using multiple methods had the advantage of facilitating comparison between the different types of qualitative methods and compensated for any individual limitation (Shenton 2004).

Data methods

The three different data methods employed in the study are discussed in further detail below.

Quality of life questionnaire (QOL-AD)

This study used a quality of life assessment tool as one of two methods to explore the impact of dementia on the lives of people WDLA. As stated in Chapter One, the assessment of quality of life (QOL) is recognised as a significant component in ascertaining the real impact of a disease (Cahill et al. 2004; Wetherell & Wetherell 2008). In addition, research has shown that QOL is a key parameter in the treatment of dementia for people with a cognitive impairment (Logsdon, McCurry & Teri 2007). In spite of its importance and the evidence demonstrating that people with mild to moderate dementia can provide reliable responses, no specific QOL studies on people WDLA were identified in the literature (Logsdon, McCurry & Teri 2007; Moyle et al. 2007). This study addresses the gap and provides greater understanding on how people WDLA perceive their QOL.

Furthermore, as discussed in Chapter 1 a challenge when designing research studies with cognitively impaired individuals is often that extra steps are required to ensure reliability of the data, such as the presence of a carer during an interview process. This approach was not suitable for this study as some of the participants' WDLA did not have a carer who could act in this role. To overcome issues of reliability, the use of more than one data

method (QOL questionnaire and semi-structured interviews) enabled investigation of the consistency of responses from people WDLA across the two methods adding rigour to the research design.

The QOL-AD scale was chosen because it is the Australian Government's recommended dementia-specific health-related QOL measurement tool (Sanson et al. 2007). In addition, this tool uses simple language and is brief, taking only five to ten minutes to complete, which is of benefit in research with people WDLA (see Appendix 5). A further reason for the selection of this tool is that it is designed to obtain a rating of a person's QOL from their perspective and that of their carer, or, in this case, the advocate (Logsdon et al. 2002). Research has shown that people with dementia usually rate their QOL significantly higher than their carers do (Steeman et al. 2007). Using the QOL-AD scale enabled comparison of the responses of the person WDLA and their advocate. It was important to ascertain whether there was a shared perspective between the person WDLA and their advocate since the advocate's role is to understand their client and potentially to represent their wishes in the decision-making process (Wells 2006).

The QOL-AD scale contains 13 items within five domains: 'perceived QOL', 'behavioural competence', 'psychological status', 'interpersonal environment' and 'physical functioning' (Logsdon et al. 2002). There are four available responses: poor, fair, good, or excellent, each of which is rated on a four point scale, with one being poor and four being excellent. The total scores range from 13 to 52 points with more points indicating a higher QOL. Permission to use the tool was obtained from the author (Logsdon et al. 2002). Using this tool, a recent study found that people with mild cognitive impairments had lower total scores than people without a cognitive impairment, and they had significantly lower individual item scores in seven of the thirteen items: energy, humour, memory, closest relationship, friends, ability to do things for fun and

ability to do household chores (Bárrios et al. 2013). A further aim of this study was to assess whether similar decreases in quality of life parameters were observed in people WDLA.

Advocates were asked to complete a QOL-AD questionnaire for each of their respective clients participating in the study. The questionnaires were provided electronically and the completed forms were given to the researcher on the day of the advocate interviews.

Subsequent to the consent process and prior to the semi-structured interviews, clients of the advocacy service, that is people WDLA, were asked to complete the QOL-AD scale during an interview. For seven of the nine participants, it only took five to ten minutes to complete, but it was not feasible to complete with two female participants. In one situation the female participant (Ann) was happy to share her opinion on the items but was unable to provide a single word rating of poor, fair, good or excellent for individual items. In the second situation the female participant (Sally) appeared uncomfortable when asked to rate different items and tended only to respond with the word 'okay'. The researcher considered it in the best interests of the participants not to continue with the QOL-AD scale and moved onto the semi-structured interview. While this tool provides quantifiable data, the main objective of its use in this study was to compare what was said across data methods (QOL questionnaire and semi-structured interviews) and data sources (advocates and people WDLA). Therefore, as the bulk of the analysis is interpretative, this overall study is considered to be qualitative (Strauss & Corbin 1998). These QOL results from people WDLA and advocates are discussed in the following chapter.

Semi-structured interviews

Qualitative interviewing was chosen because it facilitated an in-depth understanding of the phenomenon under study and explored how people view their own experiences and the meanings attributed to them (Bond et al. 1989; Hansen 2006). It is also a widely

accepted and increasingly popular method in dementia research as it facilitates communication with the person with dementia (Innes 2009; Moore & Hollett 2003). This method has been successful in obtaining the views of people in the mild to moderate stages of dementia and in providing a greater understanding of their experiences of living with the condition (Innes 2009; Steeman et al. 2006). A semi-structured interview format was used as this allowed the researcher to address specific research questions rather than examine the individual's experiences more holistically (Kelly 2010). The use of interview guides (see Appendix 4), with suggested questions and prompts, provided structure to each interview although it did not inhibit the researcher asking additional questions which freely emerged as the interviews progressed (Kelly 2010). A semi-structured approach also had the advantage of increasing the comparability of data between interviewees.

Each interview lasted approximately 60-90 minutes and all interviews were audiotaped. The interviews were independently transcribed verbatim by an external contract organisation and were checked for accuracy by the researcher. The individual transcripts were not sent to interviewees as it was considered that this had the potential to lead to confusion and emotional upset for some participants (Angen 2000). Furthermore, Creswell (2009) considered that member checking is best done with 'polished' (p. 191) interpreted data rather than the actual transcripts. Consistent with this approach, the themes and patterns emerging from the data were discussed and presented to supervisors, research peers and other academics, and the advocacy organisation participating in the study. The steps taken are discussed in more detail under the section on analysis of data.

Focus groups

Focus group was the predominant method employed for the collection of data from healthcare professionals. This method has become increasingly popular in health and social science research and has also been shown to be beneficial in the study of more

marginalised groups, such as people WDLA (Kidd & Parshall 2000). One advantage of using focus groups is that they allowed the researcher to ask healthcare professionals to share their experiences of the advocacy service and the diversities and similarities of their experiences emerged in responses to the questions posed (Mason 2002; Morgan 2004). These comparisons between participants helped stimulate interaction and discussion within each group (Morgan 2004). The focus groups were structured, in that a standard set of questions was asked of all groups (see Appendix 4). This standardisation not only guided the discussion and ensured the research questions were addressed but also facilitated the analysis of data and the comparison of responses within and between the different groups (Morgan 2004).

Healthcare professionals were divided into groups with similar roles or professions. This segmentation had two aims: first, to facilitate discussion by allowing for commonality among group members; and second, to explore whether differences in understanding and experiences of the advocacy service exist between professions (Morgan 2004). There is a risk with focus groups that participants may feel unable, or lack confidence, to express their views, but placing participants into groups with similar roles served to minimise this concern (Morgan 2004). Three focus groups, composed of nine, four and five people respectively, were conducted. The recruitment and specific composition of each group is discussed in the data source section. Small groups were chosen over large groups as they generate high levels of participant involvement, and allow each participant more time to discuss their views and experiences on dementia advocacy (Morgan 2004). Prior to commencement of the focus groups, participants were reminded of the importance of maintaining confidentiality.

Two people were present at each focus group interview: the researcher and the primary supervisor. The role of the researcher was to act as a moderator, to manage the group

dynamics, to ensure all participants contributed and to summarise the discussion at the end of each question to confirm participants' perspectives (Morgan 2004). This approach is consistent with Denzin and Lincoln (1994), who considered that focus group member checking should be done in real time. The supervisor's role was to take detailed notes of the order of speakers and to act as an observer. Immediately after the completion of each focus group, a debriefing was conducted between the researcher and supervisor. The purpose of this debriefing was to identify some of the major themes emerging from each group, and to discuss the group dynamics and the researcher's role as moderator. In the course of these discussions, major themes, patterns and motivational elements were identified. Each focus group lasted approximately ninety minutes. All focus groups were audiotaped and the data were transcribed verbatim by an independent organisation, checked for accuracy by the researcher and compared to the notes provided by the supervisor.

Data sources

Important factors specific to each of the three participant groups, such as recruitment considerations, are discussed under the respective data sources below.

People WDLA

The recruitment of people WDLA was a major ethical consideration in this study, and although it was important that their voices were heard, it was also crucial to ensure that participants had the capacity to participate. To address this issue the researcher considered that a person's ability to participate could be estimated from an assessment of their level of dementia, since research has shown that individuals with mild stages of dementia have the capacity to be involved in research (Feinberg & Whitlatch 2001; Moye et al. 2004). Therefore, a level of assessment was built into the initial recruitment process using the Global Deterioration Scale (GDS) (Reisberg et al. 1982). This is a simple seven-stage

functional test designed to be used by paraprofessionals, in which described changes in functional abilities relate to the different stages in the dementia trajectory (see Appendix 1). Stage 4 of this scale corresponds to mild dementia, while Stage 5 describes a person who is unable to recall major relevant aspects of their current lives. Therefore, people WDLA at Stage 5 or higher were omitted from the study as there was a reasonable chance that they would not be able to recall their experiences of the advocacy service. Consequently, the eligibility criteria for this study only permitted participation of people WDLA with a result of Stage 4 or lower who had used the advocacy service in the last six months.

Each advocate, who has knowledge of their clients' capacity, was asked to complete a GDS assessment on behalf of all clients they had provided advocacy for in the last 6 months. It was initially planned to recruit people WDLA from the three regions in Tasmania where dementia advocacy services are located: two from Northern Tasmania, two from North West Tasmania and six from Southern Tasmania. A greater number of people WDLA was proposed in the South as it is more densely populated, with almost 49 per cent of the population residing there (ABS 2006). In addition, the dementia advocacy service has been in existence in the South since 1997 while it is only recently been established in the North and North West. However, following completion of the GDS assessment by the advocates, only one client from the North and North West respectively met the eligibility criteria.

The advocate in the South provided the researcher with a list of all clients who scored four or less in the GDS assessment. Upon review of the each client's circumstances, the following were excluded from participation: clients currently living in residential care (ten clients); clients whose interaction with the advocate was limited (eight clients); clients with no formal diagnosis or acceptance of their cognitive impairment (two clients);

and clients whose whereabouts were no longer known (one client). Upon completion of this exercise, purposive sampling of the remaining twelve clients was conducted by the researcher and the advocate to ensure representation across ages, sexes and socio-economic backgrounds. To develop a thorough understanding of the decision-making process, including the type of decisions people WDLA face and their level of involvement, the researcher considered age, sex and socio-economic backgrounds were the most important sampling criteria. The type of decision faced by people WDLA may differ across the ages, for example the decision to cease employment may be more pertinent to people with younger onset dementia, hence the researcher considered it necessary to include representation across all ages. In addition, much of the research to date on people WDLA has concentrated on the perspectives of older women WDLA. Consequently, the researcher wanted to include the perspectives of both male and female sexes, across the different age groups, to explore whether these characteristics may influence involvement in the decision-making process. Furthermore, the researcher was also interested in exploring whether involvement in the decision-making process was influenced by the socio-economic background of people WDLA and therefore considered it important to ensure all socio-economic backgrounds were represented in the study. Although, the presence of family support, was an additional factor which may influence involvement in the decision-making process it was not part of the sampling characteristics as many of the 12 participants had no family support. Instead the influence of family support in the decision-making process was explored during the interview process. The aim of this purposive sampling was to achieve a greater depth of knowledge from a small number of participants (Teddlie & Yu 2007).

People WDLA were categorised into three age ranges: clients less than or equal to 65 years old; clients greater than 65 but less than 80 years old; and clients equal to or greater

than 80 years old. Three clients (one male, two female) fell under the younger age group, and to ensure equal representation of sexes, one male and one female were identified as possible participants for the study. The female with the most recent advocate interaction was the first choice for participation in the study. This male and female represented a high and low socio-economic background respectively. Only two clients fell within the middle age range; both were males from a relatively high socio-economic background. Seven clients (three male and four female) fell within the higher age bracket. Two clients (one male and one female) were chosen from this group based on recent experience of the advocacy service and low socio-economic background to ensure equal representation of backgrounds across all participants. All of these potential participants agreed to participate in the study.

Due to the decrease in the number of eligible participants from the North and North West, the advocate from the south was approached at a later date to see whether an additional client could be recruited to the study. It was proposed to recruit a client from the higher age group as a greater number of people WDLA fall into this age category. To ensure fair representation of sexes a female was requested. The first female remaining from the original list of seven clients declined to be involved in the study but the next female on the list agreed to participate.

Following identification of a list of potential participants, the advocates contacted their respective clients to outline the purpose of the study, using the information sheet provided by the researcher (see Appendix 3a). If clients expressed an interest in participating, the advocate scheduled an interview with the client, which took into consideration the optimal time of day for the person WDLA with respect to their capacity and organised activities. On the day prior to the interview, the advocate telephoned each participant to remind them of the appointment. On one occasion this telephone call was overlooked and

the person WDLA was not at home at the time of the interview, which had to be rescheduled. This highlighted one of the challenges of dementia research and the importance of calling to remind the person WDLA of the appointment. The advocate accompanied the researcher to each interview to introduce the researcher to the client and act as a witness to the consent process (see Appendix 2a for consent forms). Once consent was given, the advocate departed and left the researcher and person WDLA alone to proceed with the interview.

Interviews were conducted with nine people WDLA (four female and five male, aged between 49 and 86 years old) with a GDS score of four or less, who had used the advocacy service in the last six months. In one quotation, provided in Chapter Four, the previous profession of a person WDLA has been altered to protect their identity. To provide confidentiality/anonymity, each person WDLA was provided with a pseudonym and an age range rather than an exact age. Please refer to the table below for further details.

Table 4: Characteristics of people WDLA participating in this study

Pseudonyms	Gender	Age range	Family Support	Born in Australia	Born in Tasmania
Peter	Male	<65	Yes	Yes	No
Mary	Female	>80	No	No	No
Jane	Female	<65	Yes	Yes	Yes
John	Male	<80	No	No	No
Paul	Male	>80	No	No	No
Michael	Male	<80	No	No	No
Sally	Female	>80	No	Yes	Yes
Adam	Male	<65	Yes	Yes	Yes
Ann	Female	>80	No	Yes	No

The majority of people WDLA (six) participating in this study had no local family support. Four of the participants were from Europe; all, but one, were native English speakers.

The consent process is a further ethical consideration when involving cognitively impaired individuals in research. Ethical research requires that before consent is given a researcher must ensure that the person is fully informed about the research, understands that participation is voluntary and is assured that the participant is competent (Bartlett & Martin 2002). To address this consideration, approval was granted by the ethics committee to trial a capacity to consent assessment tool (see Appendix 6); in addition, it was to be ensured that the advocate witnessed the consent process. The assessment tool was based on the University of California, San Diego, Brief Assessment of Capacity to Consent (UBACC), developed and tested for outpatients with schizophrenia (Jeste et al. 2007). This is a seven-item scale that includes questions focusing on the understanding and appreciation of the key components of the study information sheet as explained by the researcher. It quickly became apparent (after two interviews) that this tool was inappropriate for use with people with dementia wanting to partake in research as it relied too heavily on the person's cognitive ability and failed to recognise communication challenges posed by dementia, such as short-term memory loss and difficulty in word

finding. It further had the potential to increase anxiety levels and cause undue stress – one of the participants viewed it as a test – and thus the tool was not conducive to building a rapport between researcher and participant. A variation removing this assessment tool and relying only on the advocate witnessing the consent process was approved by the Ethics Committee. The witnessing of the consent process was less onerous on the person WDLA but still provided reassurance on the validity of the consent.

Consent was initially requested in writing but a variation was approved by the Ethics Committee to permit either oral or written consent. There were two reasons for this variation: one person WDLA had difficulty with the physical action of signing the consent form due to their frailty, and another person WDLA, although wanting to participate, was extremely reluctant to sign a document as he was concerned he might have been being tricked into signing over power of attorney. This person WDLA agreed that he would sign the consent form at the end of the interview if he felt comfortable to do so, which he in fact did. In future research it is recommended that consent should only be requested orally to ensure that all those WDLA are afforded the opportunity to participate in research.

After completing the consent process, the interview began with the QOL-AD assessment followed by the semi-structured interview. Various measures were taken to construct a favourable environment for the interviewee such as: consulting with the advocate on the acceptability of the term ‘dementia’ (only three clients were content to use this term, all others preferred to use the term ‘memory loss’); conducting interviews at an optimal time, as individual capacity can fluctuate during the day; and performing interviews in the person’s own home using a relaxed conversational approach while acknowledging the potential communication challenges of the person. These measures adopted in the interview process are consistent with those recommended by Beuscher & Grando (2009)

when conducting qualitative studies with early-stage Alzheimer's participants (see Table 5).

Table 5: Strategies to Optimise Communication with people WDLA (Beuscher & Grando 2009)

Effects of dementia	Strategy
Attention and concentration lapses	. Conduct interview in a place with few distractions . Redirect conversation
Decreased abstract reasoning	. Restructure questions to concrete topics . Use participant's language
Difficulty word finding	. Allow plenty time to respond . If participants seem uncomfortable, offer reassurance and assistance
Fatigue or anxiety	. Monitor for signs . Offer to stop interview
Memory loss	. Use reminiscence . Provide cues
Repeating phrases	. Validate meaning . Redirect conversation

Some emotional and practical challenges arose from the interviews with people WDLA.

The need for reassurance was identified as an important factor to consider when conducting interviews with people WDLA. Two female participants (Mary and Ann) sought constant reassurance that their responses to questions were making sense and providing valid contributions. A further challenge faced by the researcher was the emotional distress displayed by three participants (Jane, Michael and John). In the case of Jane and Michael, this distress was demonstrated during questions on their future, while for John it was reminiscing about his deceased wife and thinking of a future without her. During these periods, participants were asked whether they would like to stop discussing the specific topic or end the interview, but all of the participants chose to continue. Counselling services were offered to all three participants but were declined. The practical challenges the researcher faced related to participants' loss of memory. As previously discussed, one person WDLA (Mary) had forgotten about the interview,

causing the interview to be rescheduled. Another difficulty which arose was the lack of recollection of their participation in the study. John telephoned the researcher two days after his interview to explain that he was too busy to participate; he had obtained the researcher's number from the information sheet. The researcher explained to John that he had already participated in the interview and asked whether he was comfortable with his information being included in the study. John agreed that his data could be used, following reassurance that his contribution would remain anonymous. In spite of these challenges people WDLA wanted to participate in research and many were of the view that if it might benefit others in the future it was a positive thing to do.

The interview guide addressed questions on the impact of dementia/memory loss, participation in decision-making and the advocacy experience for people WDLA (see Appendix 4a). All of the participants were able to provide responses to questions on their dementia/memory loss but not all participants were able to recall their advocacy experiences. These findings are discussed in the following two chapters.

Dementia advocates

Four advocates, including the head of the advocacy organisation and three dementia advocates working throughout Tasmania, participated in this research study. The purpose of interviewing across all levels of the organisation was to explore whether there were shared perspectives and understanding of the dementia advocate role. The aim of the research was presented to the organisation and each advocate was emailed a copy of the information sheet (see Appendix 3b), with a follow-up phone call being made to outline what participating in the study would entail for them. This participation included: completing GDS assessments on behalf of their clients; contacting proposed clients to explain the study and confirm their interest; scheduling the interview times; completing

the QOL-AD about their clients; witnessing the consent process; and participating in semi-structured interviews with the researcher.

Advocate interviews were conducted prior to interviews with people WDLA, which had the added benefit of preparing the researcher for the interviews with the participants. Understanding the support provided by the advocate, and the reasons for the initial referral, enabled the researcher to provide prompts as necessary when interviewing the person WDLA. It also allowed the researcher to explore how advocates perceive their role and how the client views the advocate's role. All advocate interviews were conducted at their place of work and lasted between 60 and 90 minutes. Advocates were asked a range of questions using an interview guide (see Appendix 4b) which included questions on their role, consent and capacity, perceived benefits, relationships with their clients and healthcare professionals and the advocacy model used by the organisation. Upon review of the sensitivity of the data, and following discussions between the researcher and the supervisors, it was considered appropriate to provide the same pseudonym to all four advocates to mask their identities.

Healthcare professionals

In order to fully explore the mechanisms which influence agentic action, it was important to consider the perspectives of healthcare professionals. These professionals play a significant role in the lives of people WDLA as they are often responsible for the provision of services, the evaluation of care needs and the assessment of a person's capacity to participate in the decision-making process. The advocacy service is also reliant on these professionals to refer clients to them, so their views and experiences of the service were crucial to understanding the features of an effective advocacy model.

Healthcare professionals' perspectives were sought only after completion of the interviews with advocates and people WDLA, as information gathered from these

interviews was used to generate the interview guide for healthcare professionals (see Appendix 4c). Healthcare professionals with experience of the advocacy service were recruited to the study from four key areas: assessment of care needs; community care provision; home and social support; and medical care.

The healthcare professionals from a medical care background, particularly general practitioners, proved extremely difficult to recruit. Two geriatricians with extensive experience of advocacy service and people WDLA were recruited through a member of a local dementia research network group of which the researcher was also a member. Membership of this local dementia research network group was a useful recruitment tool, particularly for medical professionals. In Tasmania, it is recommended that researchers not make direct contact with medical practitioners and that all requests for their participation in research are sent to a central organisation called GP South. This group provided medical practitioners with information on the study and it was expected that medical practitioners would contact the researcher to confirm their interest in participating. No medical practitioners contacted the researcher through this process, but during informal discussions with known practitioners, one practitioner with some experience of the advocacy service agreed to participate in the study. One possible explanation for slow recruitment, which emerged from focus group interviews of other healthcare professionals, is that medical practitioners normally do not refer people WDLA to the advocacy service and would have limited experience of advocacy. As their knowledge of the service is restricted, further efforts to recruit medical practitioners were abandoned. A further challenge with involving medical professionals was the inability to coordinate a mutually convenient time and location for the conduct of a focus group. To overcome this difficulty, semi-structured interviews were performed with all three

medical professionals at their places of employment using the same set of structured questions asked of the other focus group participants.

All other healthcare professionals recruited to the study were placed into one of three focus groups: assessment; community care; and home and social support. Healthcare professionals from the assessment group (eight females and one male) were recruited through the Aged Care Assessment Team (ACAT), which is responsible for assessing the care needs of people WDLA. The Service Manager was initially contacted by telephone to explain the purpose of the study, and a copy of the information sheet and an invitation letter (see Appendix 7) for all assessors with experience of the advocacy service was provided by email. Following confirmation of interest, a focus group was undertaken with participants after a regular monthly meeting at the ACAT office.

There were four community care participants with experience of the advocacy service (three female and one male), comprising three social workers and one nurse practitioner. The names of these participants had been provided to the researcher through members of a dementia research network and an email containing an invitation letter and an information sheet on the study was sent to each participant. A follow-up phone call was made to confirm interest and to determine a time and date appropriate for all. The focus group was held in a meeting room of the University of Tasmania.

The home and social support group consisted of five professionals (three female and two male). Three members were from two different home care services, one member was from the Alzheimer's Association and the remaining member was from a day care centre for people with dementia. One home care service was known to the researcher through the dementia research network, and, following confirmation by telephone of their interest to participate, the information sheet and an invitation letter were sent by email. Two

members from this organisation, with experience of the advocacy service, agreed to participate in the study. Three other home care service organisations were contacted by telephone using the telephone directory. Only one of these organisations had direct experience of the advocacy service, and the employee with the most experience agreed to participate in the focus group. The Alzheimer's Association and the day centre, two places where people WDLA get together to share in activities and social gatherings, were contacted by telephone by the researcher to request their participation as both of these organisations were mentioned by people WDLA during interviews. One member from each organisation with significant experience of the advocacy organisation agreed to participate in the focus group. The focus group was held in a meeting room of the University of Tasmania.

Collection of data from these four groups began after completion of the interviews with people WDLA. The first focus group conducted was with the assessment group, this was followed by the community care group and the home and social support group respectively. Interviews with medical professionals were the last source of data collected. All interviews from the four groups were independently transcribed and then checked for accuracy by the researcher. To protect the identity of participants, pseudonyms were not assigned to each individual but quotes from participants make reference to the group in which they participated, for example 'member of assessment group'.

Analysis of the data

As previously mentioned, Danermark's (2002) model of abduction and retroduction was used in the analysis of the data, and this six stage process is linked to the chapters of this thesis as described in Figure 3 below. Each action taken during the data analysis to uncover the generative mechanisms impacting on the power of people with dementia living alone to participate in the decision-making process is further explained under the

different stages. Stage 2 describes the first steps taken by the researcher in analysing the data from study participants. This process involved reviewing transcripts from each data source and identifying concepts which related either to people WDLA or to dementia advocacy. Once this process was complete, two initial reviews were prepared, one dealing with the experiences of people WDLA and the second addressing the experiences on dementia advocacy and the service provided from all data sources.

1. Description: A detailed literature review on the phenomena to be studied was conducted and described in Chapter Two. This provided a context for the research and identified the gaps in the literature. Chapter Three provided details on the research participants and the methodology to be used in the study.



2. Analytical resolution: All interviews were independently transcribed and entered into NVivo 8, a software package used to manage and analyse qualitative data. The transcripts were reviewed line by line and when a concept was identified it was assigned a code (or 'node', as referred to in NVivo). Texts within codes were compared to ensure they consistently reflected the assigned code. There were 16 codes arising from this process with respect to people WDLA and 34 codes relating to dementia advocacy.

***People WDLA codes:** anxiety, avoidance, awareness, decision-making, depression, family and friends, feelings about life, feelings on memory loss/dementia, living alone, reassurance, relationship with services, risk, sense of order, social interactions, the future, ways of coping.*

***Dementia advocacy codes:** attachment, benefits, client boundaries, differing opinions, power dynamics, rights, risks, trust, befriending, capacity, caseworker versus advocate, challenges, citizen advocacy, consent, decision-making, dementia advocacy, frequency of visits, differences in model, future direction, future planning, initial introduction, job-description, non-instructed advocacy, procedures, reflexivity, skills, training, relationship with healthcare professionals, benefits to support services, figures, promotion of services, when to refer, who refers, why refer*

Using these codes, two reviews were prepared which addressed the experiences of people WDLA and dementia advocacy. These reviews and the emerging nodes were themselves critically reviewed by both supervisors. Although these reviews were predominantly descriptive, it facilitated the researcher to explore, and critically reflect upon, the data and the emerging themes. It also laid the foundation for Stage 3 of the process.



3. Abduction/Theoretical redescription: The transcripts were re-read and upon critical reflection of the reviews some codes were redefined while others were grouped together where they reflected a similar theme. The use of NVivo greatly assisted this analysis as all quotes under a specific node could be reviewed and, where necessary, nodes could be easily merged. Themes were also compared across the different data methods to review consistency of responses. Theoretical explanations were evaluated against the QOL-AD results to explore whether a correlation existed between these explanations and the individual QOL-AD score.

Regular supervisory meetings also facilitated this refining process as it gave opportunity to deliberate over the developing themes and interpretations. A research journal was also used by the researcher to document the thought process and to bring clarity to the reflections. One supervisor also conducted an independent audit of the coding process by comparing two random interviews with two coding themes downloaded from the NVivo software package.

This process of redescription resulted in eight themes in relation to people WDLA and 11 themes in relation to dementia advocacy

People WDLA codes: *resilience, social interactions, decisional control, coping strategies, risks, future, home, dementia diagnosis*

Dementia advocacy codes: *benefits, boundaries, defining advocacy, barriers, capacity, risk, challenges, advocate role, abuse, initial introduction, skills*



4. & 5. Retroduction and abstract comparison. Stage 4 and 5 were combined as suggested by Danermark (2002, p. 110). For each of the components identified from Stage 2 and 3, the researcher attempted to answer the following questions: how is it possible for people WDLA to participate in the decision-making process? What properties must exist to enable agency of these individuals? What causal mechanisms promote or inhibit agency and what are the explanatory powers of these mechanisms? How is it possible for advocates to facilitate agency? What properties must the advocate possess? What are the mechanisms that impact on the advocacy model?

Peer review was used to critique these findings as this is an appropriate method when using a critical realist framework (Guba & Lincoln 2004). Peer feedback was received in five ways:

- Discussion of the findings during regular supervisory meetings
- Presentation of the findings at two international and two national conferences
- Presentation of the results to the participating advocacy organisation
- Presentation of the advocacy findings to an independent dementia advocacy organisation in another country of similar size to explore the generalizability of the explanations
- Presentation of the advocacy findings to the participating advocacy organisation.

These findings are presented in Chapters Four and Five of this thesis.



6. Concretisation and contextualisation. Chapter Six – Discussion and Chapter Seven – Conclusion address this stage in the process. In Chapter Six the mechanisms which influence the power of people with dementia living alone to participate in the decision-making process are addressed and the ways in which they emerge in different contexts are discussed. Chapter Seven presents an explanation of how this information contributes to explanations of the concrete events.

Figure 3: Process of data analysis and presentation of findings

During Stage 3 the codes from the initial reviews were redefined using critical reflection and deliberation. This process of redescription revealed eight themes in relation to the experiences of people WDLA and eleven themes in relation to dementia advocacy. During this stage the QOL data was also analysed to provide further information on people WDLA and how they perceived their quality of life. These results were compared to responses from people with mild cognitive impairments from another study to see if commonality existed or whether there are specific items that are more important to people WDLA. During this stage of analysis the QOL responses from each person WDLA was compared to their interview transcript to triangulate each participant's data and both sources showed similar patterns. The QOL responses from each participant and their perspective advocate was also analysed during this stage to assess how well the advocate's view of their client's QOL matched their clients.

The next stages in the data analysis process, Stages 4 and 5 focused on identifying the mechanisms which affect agency and participation in the decision-making process, this was predominantly achieved through critical review and peer feedback to critique the findings. The final stage in the process examined these different mechanisms and the manner in which they interact with each other under specific conditions is discussed in Chapter Six of this thesis.

Conclusion

This chapter provided a detailed explanation of the theoretical framework underpinning the study, the methodology and research methods used, and the techniques employed to ensure rigor throughout. Critical realism was an appropriate theoretical framework to choose for this study because it addresses the relationship between social structures and human agency, which was the focus of the research questions. The use of multiple

methods and multiple data sources facilitated the development of a rich, complex picture of the power of people WDLA to participate in the decision-making process.

A qualitative approach was found to be a suitable method for engaging people WDLA in research as it facilitated communication and enabled those with communication deficits to participate. However, this study identified various practical and emotional factors to be considered when involving people WDLA in research such as: the importance of oral consent; telephoning participants prior to the interview to remind them; the need to redirect conversation and provide reassurance; and the potential for emotional distress if questioned on their future. It is recommended that these issues be considered in future research with people WDLA.

A detailed account of the data collection and data analysis methods has also been included in this chapter to enable the reader to see the evidence on which the analysis was based (Cohen & Crabtree 2008). Danermark's (2002) model of abduction and retroduction was found to be beneficial in guiding the analysis and the search for underlying mechanisms. The next two chapters present the findings that emerged using the methodology outlined in this chapter.

Chapter 4: Dementia's impact on people WDLA

Introduction

The first of two findings chapters, this chapter presents data gathered from people WDLA. Data are presented from the administration of the Quality of Life (QOL-AD) questionnaire, a brief instrument comprising 13 items, completed by seven of the participants WDLA and their respective advocates. The chapter then proceeds to the findings from the semi-structured interviews, conducted with nine participants WDLA, which explores the impact of dementia on agency and the power of participants to participate in decision-making. The chapter concludes by presenting the strategies people WDLA have put in place to help cope with their cognitive impairment and to protect their agentic power.

Quality of Life Assessments

The main purpose of using the QOL-AD questionnaire was to gain knowledge about how people WDLA view their quality of life, as no previous QOL studies with this cohort had been identified. The use of more than one data method, QOL-AD questionnaire and semi-structured interviews, also allowed the researcher to assess the consistency of responses from people WDLA, thus adding rigor to the study. A further purpose in using this QOL-AD tool was to assess whether there was a shared view between the advocate and the client on the quality of life of the participant WDLA. As discussed in Chapter Three, total QOL-AD scores can range from 13 to 52 points with more points being associated with a higher QOL. The graph below presents the QOL-AD total scores from the seven participants WDLA and their respective advocate.

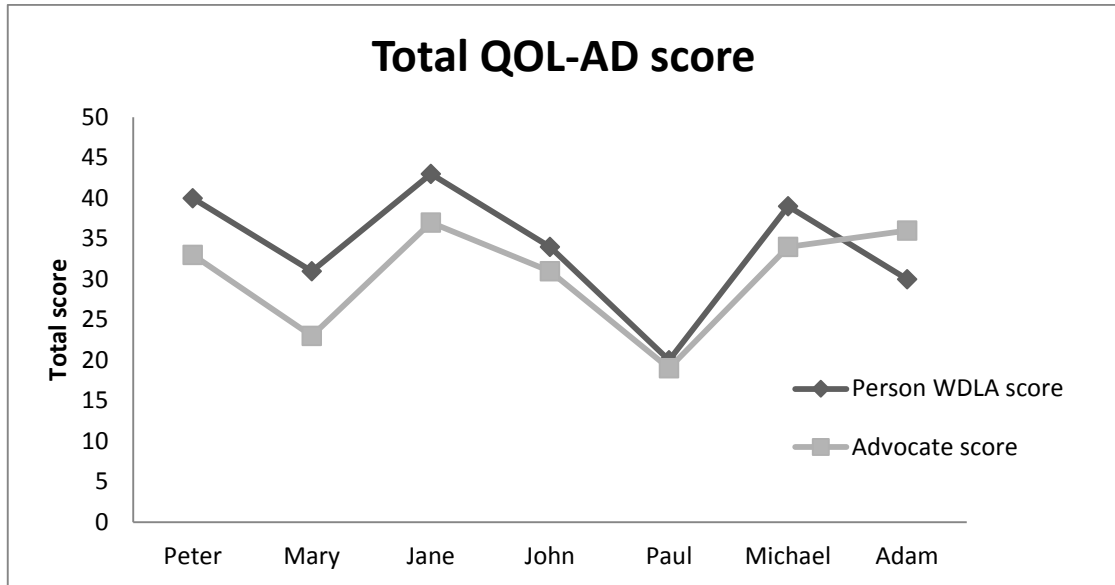


Figure 4: Total QOL-AD scores from people WDLA and advocates

The graph above shows that all seven participants, with the exception of Paul, rated their QOL positively, as total scores of 30 or greater were recorded. The graph also shows that, with the exception of Adam, participants WDLA rated their QOL higher than the advocate's assessment of their QOL. The mean score for all participants WDLA was 33.9 while the mean score from advocates was 30.4. These results were consistent with findings from another study in which people with mild cognitive impairment (MCI) rated their quality of life higher than their carers (32.1 versus 27.2) using the same QOL-AD tool (Bárrios et al. 2013).

The following graph presents the mean scores for each of the 13 items, as reported by participants WDLA and advocates. The results demonstrated broad consistency between participants WDLA and advocates, with the scores being quite closely matched for the majority of items.

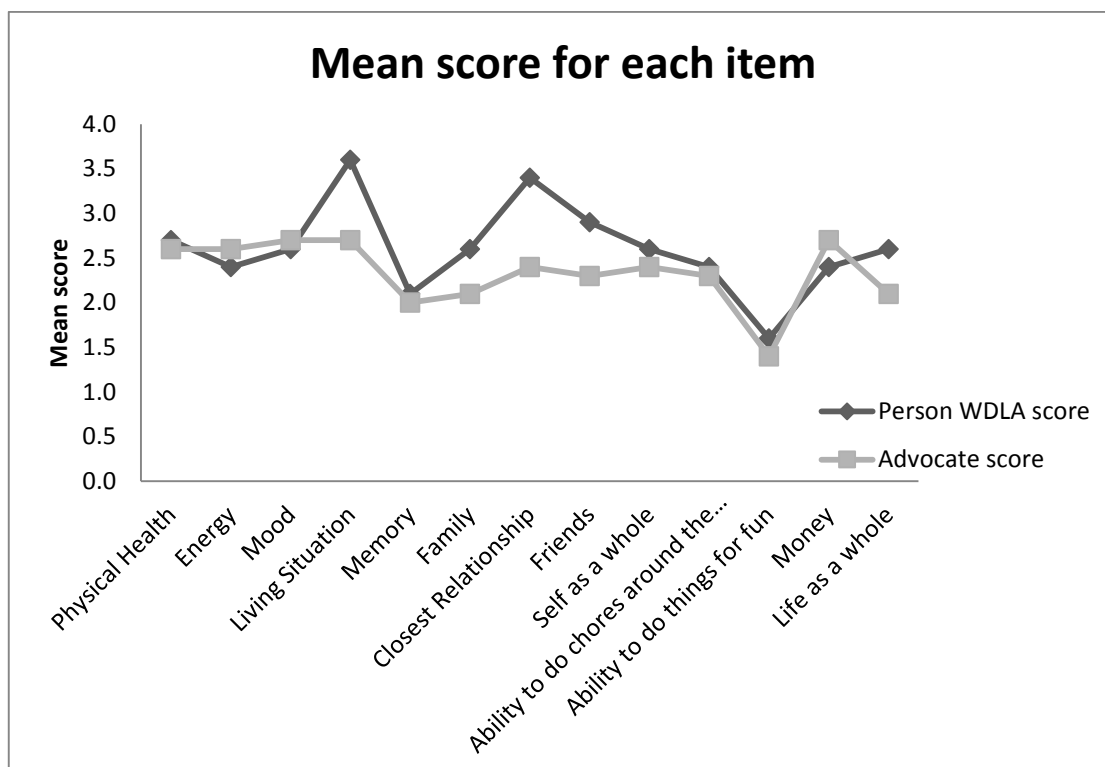


Figure 5: Comparison of mean scores for individual QOL-AD items between people WDLA and advocates

Mean scores for the items *'family'*, *'friends'* and *'life as a whole'* were slightly higher by participants WDLA. The greatest differences between participants WDLA and advocate responses were evident for two items: *'living situation'* and *'closest relationship'*. The difference in response to *'closest relationship'* can be explained by lower expectations of participants WDLA compared to advocates. The advocate provided a low score in circumstances where infrequent visits from the *'closest relationship'* occurred, while in contrast these relationships were rated high by participants WDLA as they were grateful even when communication by telephone occurred. All seven participants WDLA rated their *'living situation'* either good or excellent. This rating was consistent with the data provided during the semi-structured interviews in which participants WDLA expressed strong emotions in relation to their home and their desire to remain living there for as long as possible.

The QOL-AD individual mean scores were compared to a QOL-AD study conducted with people with MCI (Bárrios et al. 2013). For the majority of items (11 of 13) the mean scores of people WDLA in this study were higher than those of people with MCI; only two items rated lower, which were *'family'* and *'ability to do things for fun'*. The low result for *'family'* was to be expected given that the majority of people WDLA participating in the study did not have any local family support. The interview data suggest that the responses to *'ability to do things for fun'* are negatively affected by the level of social interaction of participants WDLA, which is discussed further under the individual item score results. The difference in higher mean item scores for people WDLA versus people with MCI was slight, with two exceptions: *'living situation'* (3.57 versus 2.58); and *'closest relative'* or *'marriage'* (3.43 versus 2.80), as referred to in the Bárrios et al. study (2013). Higher scores for these two items is consistent with the responses from participants WDLA and advocates as previously discussed. The QOL-AD data in this study suggest that *'living situation'* and *'closest relative'* may be particularly important items to people WDLA, while the *'ability to do things for fun'* may be lower in people WDLA with limited social interactions. The table below provides individual scores for each of the 13 items.

Table 6: Individual item scores for each person WDLA

QOL-AD Parameter	Peter	Mary	Jane	John	Paul	Michael	Adam	Total
Physical health	3	2	3	3	3	3	2	19
Energy	3	2	3	3	1	2	3	17
Mood	3	2	3	2	3	3	2	18
Living situation	3	3	4	4	4	4	3	25
Memory	2	2	3	3	1	3	1	15
Family	4	2	4	1	1	3	3	18
Closest relationship	4	4	4	4	1	3	4	24
Friends	3	3	4	3	1	4	2	20
Self as a whole	3	2	3	2	2	3	3	18
Ability to do chores	3	1	4	4	-	4	1	17
Ability to do things for fun	3	3	3	1	-	-	1	11
Money	3	3	2	3	1	3	2	17
Life as a whole	3	2	3	1	2	4	3	18
Total Score	40	31	43	34	20	39	30	

A review of QOL-AD and semi-structured interview data showed that there was consistency between data methods. The majority of participants WDLA scored their *'physical health'* as good, with the exception of Mary and Adam, and this result is consistent with information provided in the semi-structured interviews; Mary and Adam have health conditions in addition to dementia. These participants, because of poor health, also provided a low score for their *'ability to do chores around the house'*. Paul did not provide a score for this item, as he explained it is not a matter of his ability, but rather a dislike and an avoidance of doing chores. As would be expected, the total score for memory was low, with four people WDLA rating it poor or fair. John associated his cognitive difficulties with a grieving process rather than a cognitive impairment and his lack of insight was reflected in the high score provided for *'memory'*. Although Jane and Michael accepted their dementia diagnosis, both rated their *'memory'* as good as they were of the view that word finding rather than memory loss was their greatest challenge. The *'ability to do things for fun'* had the lowest overall total score; both John and Adam

rated it poor, while Paul and Michael did not provide a score. Michael explained that this item was not applicable to him as he was focused on getting his home in order and believed he did not have the time for fun. The four participants WDLA, with a low or no score for this item had almost no social interaction outside the home and very limited interaction within the home, apart from with healthcare professionals. These data suggested that a low response for the item '*ability to do things for fun*' may be an indicator of social isolation for a person WDLA.

The data showed that the majority of these participants living alone, with mild to moderate dementia, were able to provide consistent responses to questions on their quality of life and almost all of them rated their quality of life positively. It is not possible to make generalisations based on the number of people WDLA in this study; however the data indicated that '*living situation*' and '*closest relationship*' and the lack of '*ability to do things for fun*' may be important parameters to consider when working with people WDLA. The QOL-AD responses showed consistency in scores between advocates and participants WDLA, demonstrating that advocates generally have a good understanding of their clients' quality of life. This brief QOL-AD questionnaire, which uses simple language, was a useful tool in understanding how people WDLA viewed their QOL and how those supporting them, such as the advocates, perceived it. Used in combination with semi-structured interviews, this tool enabled the researcher to assess the consistency of responses across the data methods, which helped to address concerns over the validity of data from people WDLA in research.

Impact of dementia

Semi-structured interviews were conducted with nine people WDLA to gain an understanding of the impact of dementia on agency and how this may affect their ability to participate in the decision-making process. Although there were some challenges in

interviewing people WDLA, as discussed in the previous chapter, participants were able to provide responses to questions on how their lives had been affected by the condition. This study found that a dementia diagnosis resulted in a loss in functional capacity, a loss of power to participate in the decision-making process, and fear of future loss of agency which significantly affected participants WDLA. These results are discussed in detail below.

Loss in functional capacity

All participants WDLA had experienced a reduction in functional capacity leading to a loss in ability to manage responsibilities, diminished agency and an inability to participate in self-affirming activities. This resulted in a narrowing of their social world and an increased risk of harm. Loss in functional capacity led to concerns over how others perceived them and a reduction in self-esteem which resulted in some participants WDLA choosing to withdraw from social interactions, thus increasing their risk of social isolation.

Due to diminished functional capacity, many of the participants WDLA were struggling to manage responsibilities, especially dealing with paperwork and interpreting the mail they received. Evidence of this was observed by the various piles of paperwork around the homes of some participants (Mary, Michael, Paul and Ann). These participants demonstrated awareness of this and hoped that during times of greater clarity they might be able to get out of this ‘*muddle*’ (Mary, age >80). The data suggested being organised was important for these participants. For example, Ann explained:

I keep thinking when I have a clear head I'll do a bit more. I know that I probably haven't got that long to go. There's a lot of things I would like to tidy up. But the things that aren't tidy need a healthy brain to fix them. (Ann, age >80)

The majority of people WDLA in this study had led very independent lives prior to their cognitive impairment and maintaining agency was very important for them. Nevertheless, some participants had come to the realisation that they were losing power of agency and could no longer maintain responsibility for all aspects of their lives, which proved challenging, particularly for the younger participants. An example is provided below where Jane was having difficulty in completing the necessary paperwork to delegate one of her responsibilities to a family member:

I mean it took me two days and I still couldn't even get it. I just couldn't do it. And that was really upsetting to me because I just wanted to do it because, you know, just ... yeah but anyway. (Jane, age <65)

The realisation that these participants could no longer manage their responsibilities and exert power of agency affected their self-esteem, particularly when comparing previous capabilities to current capabilities, as Mary explained:

I thought I was invincible. I thought I was a strong woman and invincible (Mary, age >80)

The data also indicated that losing the ability to manage responsibilities made some people WDLA feel like they were losing something of themselves while also decreasing their own standards, as exemplified by Mary below:

I've got to get organised here. If you saw the rest of the place, it's up to its eyes in clutter, clothes and – it's not that bad really, but it is you know. It's not what I used to be. (Mary, age >80)

In recognising they could no longer manage certain tasks alone, some participants WDLA spoke of the relief they experienced at having someone in their lives that they could rely on to assist them. A key factor in accepting support was trust in the person that they

would not try to take over other aspects of their lives but would only get involved as requested by the person WDLA. For example, as Peter explained:

I rely on my son Max certainly more than I used to but he doesn't sort of press himself on me and I can go to him and he's been terrific actually. (Peter, age <65)

It was also important that participants WDLA trusted that the person providing assistance would not take advantage of their cognitive impairment. For example, Mary acknowledged, as quoted, below that she would appreciate the support of others but was reluctant and cautious about trusting others:

It's nice to have someone to talk about it (financial matters), but then you have to be careful who you are talking to about things don't you? (Mary, age >80)

These results showed that participants WDLA were losing capacity to exert agency over their responsibilities, which can lead to diminished self-esteem, but that with the support of a trusted person, they could continue to maintain power of agency over these responsibilities. In order to accept support, the person WDLA needed to be confident that the person providing support would restrict their assistance to the requests of the person and not take advantage of their cognitive impairment or diminish their agentic power.

Narrowing of the social world

Due to a loss in functional capacity, seven people WDLA were no longer able to drive. Losing this ability significantly constrained power of agency as it limited participants' ability to shop, attend appointments, visit friends and participate in hobbies. This loss induced feelings of frustration, as along with restricting power of agency, it also increased participants' reliance on others. For example, Mary used to depend on her car for everyday living as public transport was not easily accessible in her locality. Since losing the ability to drive she has become reliant on others to take her shopping. Mary found:

...the most frustrating thing was not to be able to get out and get in the car, and go down the shop, and get a loaf of bread, and a pint of milk, or whatever [it] might be, and it's frustrating. I couldn't go and see anyone. (Mary, age >80)

Loss of the ability to drive considerably narrowed the social world of these participants WDLA, as for some, such as Mary, they could no longer choose to visit friends, while for others it meant they could no longer participate in hobbies. Withdrawal from hobbies and personal interests had a major effect on the lives of some participants WDLA as participation in these activities formed part of their identity, as Michael explained:

My hobbies were hunting and fishing. Yes, that was my life actually. And now nothing. (Michael, age <80)

Friendships, particularly for male participants such as Michael and Adam, were often associated with these activities, and once participation in their activities was discontinued contact with these friends was also lost. Loss of the ability to drive limited opportunity to participate in these self-affirming activities and reduced the level of social interaction of participants WDLA.

A further factor which contributed to a narrowing of the social world of people WDLA, particularly younger participants, was giving up employment. Three people WDLA from the study had faced this situation and the data indicated that participants tended to delay the inevitable for as long as possible, as Jane explained:

There's no way I could function anymore. And I knew that. I knew that that was part, that was very distressing as well because I knew that I had to give up work so I kept stretching it along and I thought I can't do this anymore. (Jane, age <65)

These younger participants WDLA not only lost the ability to participate in a self-affirming job but they also missed the opportunity of '*just meeting people you know, and discussing things with people*' (Adam, age <65). Loss of employment limited the

opportunity for social interaction and contributed to feelings of loneliness for these participants.

Loss of memory was also found to be a significant factor in narrowing the social world of participants WDLA. For example, because of poor memory, two male participants, Paul and Adam, no longer left their own home alone for fear of getting lost. Along with constraining power of agency, this loss also increased the risk of social isolation, as Paul explained:

I'm scared to walk off down the road and then I worry about getting back because I tend to go too far and find I couldn't get back. I've thought about getting a dog, because you just let the dog go. The dog would turn up here. I think someone would say there's my dog, where is he? The dog would take them back to me. (Paul, age >80)

Both Paul and Adam had a very limited number of family and friends visiting them at home. To overcome his feelings of loneliness, Adam no longer used his own bedroom, but slept on the sofa with the television on for company. Because of this practice he only managed to sleep four or five hours per night which may lead to further negative health outcomes. Due to a loss in functional capacity and diminished power of agency these participants WDLA were at risk of being socially marginalised.

Increased risk of harm

Loss in functional capacity, specifically memory loss, was found to directly or indirectly increase the risk of harm for participants WDLA. This was evidenced by the experiences of two participants, Adam and Ann. In Adam's situation, his fading memory and loss of power of agency led him to hand over management of his finances to a trusted family member who then abused their position. It is unclear how long the abuse was occurring; Adam's loss of memory and his limited support network left him vulnerable and the abuse only stopped following advocate involvement. These results showed that a trusting

relationship, along with enhancing power of agency as discussed previously, also has the power to exploit the person WDLA. In the second example, from Ann, it was again the loss of memory which rendered her susceptible to mistreatment. Ann had cancelled her cheque book because she had misplaced it but subsequently found it again, and, forgetting she had cancelled it, began using it again. This led to a cheque bouncing and the recipient, unaware of her condition, confronted her one evening in her own home. Ann usually left her front door unlocked and she explained:

He opened the door... [he] came screaming into the kitchen, and I looked up and [I was] rather frightened. [He said] 'You've no right...'... He's still raving and ranting, so I sort of hoped that he would go. So he eventually went. And I was paralytic when he went...I was scared. But honestly I think that was something I could have died over. The brutality of it. He didn't hit me. But it was just as bad. Probably worse than if he'd just given me a punch... (Ann, age >80)

This experience significantly affected Ann and reduced her power of agency as since then she had been reluctant to leave the safety of her own home. These results suggest that a community that has an awareness of a person's deficit may provide a more supportive and understanding environment, thus reducing the risk of harm for people WDLA. However, achieving this awareness may be difficult, as Ann explained:

I can't sort of put a sign around my neck 'be careful I'm going to go silly in a minute'. (Ann, age >80)

Loss of meaningful activity, such as employment, was also shown to increase the risk of harm for some participants WDLA. This loss had the potential to create a void in a person's life, and the search for a replacement activity or purpose could increase the risk of exploitation by others. Ann again provided an example of this; she spent a significant amount of time and money on international lotteries. Ann explained that completion of the lottery forms '*occupies quite a bit of my time*' and although she was not interested in

winning, completing the forms correctly was providing her with a sense of purpose and pride. She had been advised of the strong possibility that these lotteries were scams and even though she appeared to understand this she could not comprehend the concern over how she spent her money. The amount of money spent on these activities led her bank manager to visit her at home to express the bank's concern and to try to deter her from this activity. In response to this, Ann opened another account to hide her spending and to avoid further discussion, as Ann explained:

I spent a lot of money on these 'scams' as you call them. I don't call them scams. But it keeps me alive. But I was so embarrassed that the bank manager had to come down for three hours when she'd just come back from holidays that I opened another account in case I had all this. (Ann, age >80)

These results showed that loss in functional capacity and a search for self-affirming activities can lead to an increase in the risk of harm of some people WDLA. Awareness of the community about the person's deficit has the potential to reduce or increase their risk of harm. It is worthwhile considering for future research how this awareness could be provided to the community while at the same time also ensuring that mechanisms are in place to protect these people WDLA from potential financial exploitation.

Concern over the judgements of others

The data indicated that there was a stigma associated with a dementia diagnosis; while the majority of participants accepted having memory loss, only three participants were comfortable to refer to their condition as 'dementia'. A major factor in using the term 'dementia' related to a concern over how others would perceive them, as Peter explained:

There was a time, I thought, that was the end, the onset of Alzheimer's. I wasn't really able to face anyone. (Peter, age <65)

The concern over the reaction of others and embarrassment about their loss in functional capacity and diminished power of agency resulted in some participants WDLA choosing

to withdraw from interactions with others. This concern has the potential to increase the risk of social isolation for people WDLA, as Jane explained:

I don't like people seeing me that way, you know, either. None of it is ever pretty. (Jane, age <65)

The worry over other peoples' judgements was so severe that it even led one participant WDLA, Ann, to move to a different State, where she knew no one and no one knew her. Ann wanted to be remembered for who she was and not for who she was becoming. Ann explained:

I chose to come to Tasmania where nobody knows me...So they couldn't place one against the other sort of thing ...I just thought that was far enough away from my life. (Ann, age >80)

Although Ann's move to a different State achieved her objective, it also removed her from any existing support network and left her socially isolated. This is an example of how fear of the judgements of others can significantly increase the risk of social isolation for people WDLA. Yet, as Ann explained, she would prefer to be socially isolated than to be treated as '*that queer woman up the road, or something like that*'.

Many of the participants WDLA appeared also to be concerned with the interviewer's impression of them, and it seemed important to them that they portray themselves in a positive light. To mask their cognitive impairment, two of the participants, Peter and Jane, had cultivated an ability to redirect questions that they may have had difficulty in answering during the interview process. For example, when asked '*Would you like the advocacy service to be doing anything different or anything else in your situation?*' Peter responded by saying:

That's a good question. What sort of things are they doing these days then? Maybe there's new things that I might not be aware of. (Peter, age <65)

In addition, several of the participants wanted to share stories, photographs and trophies of previous achievements with the interviewer. It appeared that these participants WDLA wanted the interviewer to know that they were once capable and successful individuals prior to their cognitive impairment. For example, Mary insisted that the interviewer look at photographs of her playing the piano in a band, an example of a sentiment expressed below:

You want proof? But you're going to get proof, like it or not. (Mary, age >80)

It seemed that recalling past achievements helped some participants WDLA to sustain their self-esteem, as shown by this example from Mary:

...the teacher said, "You'd have been a professional musician, pianist you know." She told me a few years ago. And I know. I'm pretty certain that I could have done it. I don't mean to be big-headed or anything like that. (Mary, age >80)

The converse was also observed where recalling previous capacities had the potential to diminish self-esteem in participants WDLA, as exemplified by Adam:

I used to be a boxer and I could fight my way out of anything. But now I'm just too scared to go out of my own street. Which is really disappointing. (Adam, age <65)

For many participants WDLA the loss in functional capacity and power of agency had led to diminished self-esteem, with words such as '*frustrated*', '*disgusted*' and '*disappointed*' used in the interviews in reference to their losses. Moreover, some of the participants demonstrated low self-esteem by making self-deprecating comments during the interview, as exemplified below:

If you put up with my nonsense, you put up with anything (Mary, age >80)

While others frequently felt the need to apologise for their deficits throughout the interview – ‘*I probably jumped all around the place, sorry*’ (Jane, age <65). These results showed that people WDLA were concerned about how others perceived them; this concern, and a reduction in self-esteem, may lead them to avoid interacting with others.

Loss of power to participate in the decision-making process

It was important to all people WDLA in this study to remain in control of their own decisions, yet in spite of this, the majority of participants had experienced marginalisation in the decision-making process. This marginalisation was due to the disenfranchising actions of others involved in their lives, who were often well-meaning family and friends. Participants WDLA responded in different ways to this exclusion from the decision-making process; some participants chose to confront it, while others felt powerless to do or say anything about it. The following three vignettes provide examples of this exclusion and the reaction of the participants. In the first example, Mary chose to confront her marginalisation from the decision-making process, which resulted in a narrowing of her social world.

Box 1: Mary's experience

Mary had no immediate local family support, but she had a very close friendship with Beth for almost forty years. Following Mary's diagnosis the dynamics of their relationship changed. Beth, as a concerned friend, began to take control over Mary's decisions but Mary felt excluded from conversations and decisions about her own life. Mary's perceived loss of power to participate led to an argument. Mary explained:

...it's a bit spoilt with that little blue that we had, but she [Beth] was sort of taking over, and people come in like Paula [the advocate], and different ones, and she was doing all the answering. It left me – I wasn't part of it. You know? And in the end I hit the roof. So did she. (Mary, age >80)

Mary did not want her diagnosis to have an impact on her relationship, nor did she want to be treated differently. It was very important for Mary to remain involved in her own decisions and although others may have judged her incapable, she did not want them to speak about her life as if she was not there and thus remove her agentic power. Mary stated:

Well it got too much with everybody talking – as if I was a nincompoop. Perhaps I was, but they didn't have to let me know. (Mary, age >80)

Mary was asked during the interview if she felt more in control of her life since the argument and her response was:

Yes. Because I'm not being dominated over. And I was treated as if I was an idiot. (Mary, age >80)

As a consequence of this quarrel, Mary and Beth were no longer in contact and although Mary felt more in control of her life, her social network had diminished and she had lost the support of a very close friend.

In the second example, Sally described a situation where her partner's adult children made a decision in her best interests without involving her in the decision-making process or attempting to learn her perspective. In contrast to Mary, Sally remained silent, as she believed there was nothing she could do to alter the situation and restore her agentic power.

Box 2: Sally's experience

Sally had never lived alone; she had lived with her partner for over 35 years and before that she had lived with her mother until her death. Sally spent some time in hospital and rehabilitation following a fall and during this period her partner's children decided to put their father into a nursing home. Her partner had a condition which required support, and the adult children formed an opinion that Sally was no longer able to care for him appropriately. The first night Sally spent alone in her home was the night she came home from rehabilitation. Sally explained:

...and of course they eventually got him into [name of home deleted], the nursing home. Well that meant that he didn't have to... he couldn't live here no more because he wasn't capable, and they said I wasn't capable of looking after him because I was too frail. (Sally, age >80)

Sally was not happy with the outcome but believed she had no choice but to accept the decision of her partner's children; as Sally put it 'you've got to go along with it'.

Although this decision had a major impact on her life, she was excluded from it. She now spent four days a week visiting her partner in the residential care facility and explained that it was very costly given that the facility chosen by her partner's children was not close to her home. Sally's loss of power to participate in the decision-making process has had significant emotional and financial consequences for her life.

The third example from Jane is similar to Sally's experience where she felt unable to say anything about her feelings of exclusion from the decision-making process. However, in Jane's situation, she was very aware that she would be dependent on her family in the future and this awareness made her reluctant to discuss her feelings about her marginalisation in the decision-making process, as presented in the following vignette.

Box 3: Jane's experience

Jane believed she no longer had control over all of her decisions, as she considered that her family had started to make small decisions without her knowledge or at other times had tried to influence her decision-making. Although she found this frustrating, she believed that she must come to terms with the loss of agentic power and learn to be more appreciative of her family's support and the fact that they were 'looking out' for her. Jane said:

I think to myself that's awful for me to think that because they're doing the best they can and they're doing it for me. So you know I've got to get over that. (Jane, age <65)

Jane was very much aware of the fact that she would be dependent upon her family in the future and it was this awareness that inhibited her from speaking out over her loss of power to participate in the decision-making process. In regards to remaining silent, Jane said:

I get a bit upset about it, but I try not ... I mean I guess in a way you know I'm going to be quite dependent upon them you know, so I've got to. (Jane, age <65)

Beyond the actions of family and friends, some people WDLA believed their decision-making control was diminished by the actions of home support service professionals. These professionals provide a service to people WDLA according to a given schedule, and some people WDLA were of the view that they had limited input into the timing and delivery of the service. For example, Ann found there were some days when she did not feel very well and did not want to make use of services, but when she tried to express her feelings she did not feel heard. Ann thought these professionals were dismissive of her wishes and this had led to some tension between her and the home support service professionals.

Moreover, decision-making control was so important for some people WDLA that it resulted in reluctance to engage with others for fear of losing control. For example, during the interview with Paul it came to light that he had refused to sign a consent form the

previous week which would have granted him access to support services. Although, it was evident that Paul needed further support, he did not want to sign any document as he was afraid he would be tricked into signing over power of attorney, which would result in a loss of agentic power, including decision-making control. His mistrust of the intentions of others made interacting with him challenging; he could be very confrontational, as was witnessed during the initial stages of the interview until trust was established. His hostile manner is demonstrated in this excerpt:

...if I want to do anything I just go and do it. I've had people in your circumstances come and say 'We can stop you going there', and I said 'Have a go mate'. No, people say 'You can't go to New Zealand in your condition' and I say 'Why the hell can't I?' They won't let you go. Who's they? And that's a lot of hooey. I can't be stopped doing anything I want to do. (Paul, age >80)

Similar to Ann, Paul felt that he was not listened to by healthcare professionals; he was of the view that his decisions were shaped by his life history but considered that healthcare professionals were making judgement calls about the way he lived his life without taking time to understand the context of his decision. Paul explained:

I worry about sort of you always turning up here, or girls saying "But you can't do that". And I say who the hell says I can't do that. ... But then they have no conception about what my life has been like. (Paul, age >80)

Paul was very socially isolated and his confrontational manner may lead to further isolation. The interviewer found that time was needed with Paul to overcome his mistrust and move past his hostile façade. Paul may be disadvantaged if healthcare professionals do not have that time to spend with him, and his reluctance to engage with others may be detrimental to his overall well-being.

These results showed that participants felt marginalised in the decision-making process and that their agentic power was being constrained by the cultural contexts of others

around them. Individuals reacted differently to the actual and potential loss of power to participate in the decision-making process, while exclusion from this process had the potential to negatively affect the lives of participants WDLA.

Fear over future loss of agency

Fear of future loss of agency was identified as a major concern for participants WDLA, particularly younger participants. Due to this fear, participants preferred not to spend time thinking about the future as they found it too emotionally distressing. Fear was expressed by participants of the unknown, of being a burden and of future decision-makers. For example, Adam, the youngest of all participants, was very concerned about what may lie ahead and what would happen to his estate after his death. By contrast, Jane's concern was with being a burden on her family, and she acknowledged she was fiercely independent and feared future dependency and loss of power of agency. In response to this fear she had even gone as far as organising her own funeral, without the knowledge of her family. Regarding her exerting power of agency in this way, Jane said:

...it empowered me actually. It made me feel like, you know, I've done this by myself – all myself. (Jane, age <65)

Jane became extremely upset during the interview when discussing her future and expressed a wish to end her own life if it was legal to do so. Not only was she worried about losing control and being a burden, she was also concerned about the impact on family members of witnessing her deterioration; as Jane explained:

I mean, to be honest, if I had the choice I'd have that needle. (Jane, age <65)

Michael also became very upset during the interview when discussing his future and expressed similar sentiments about a wish to end his own life. In contrast to Jane, Michael was extremely concerned about the loss of decision-making capacity and his future

decision-maker. Michael's son, his only immediate family member, wanted to be responsible for Michael's decisions when he no longer possessed decision-making capacity, but Michael was not happy about his son taking on this role. Michael explained:

He would look after [me], but I don't want to live like this. (Michael, age <80)

The difficulty for Michael was that he and his son were very different and, as he explained, had generally conflicting perspectives of the world. Because of that, Michael said he would prefer to have the right to end his own life rather than face this future. Jane and Michael both had experience of the dementia trajectory, each having witnessed the deterioration of a parent with the same condition, and this may have heightened their fear of future loss of agency. Nonetheless, the majority of participants WDLA preferred not to spend time thinking about the future or discussing it with family members as they found it too emotionally distressing and preferred to take life one day at a time. Adam explained:

I'm not ready for it yet. Know what I mean? (Adam, age <65)

The results showed that participants WDLA – particularly younger people – feared future loss of agency, and were particularly fearful of the unknown, dependency on others and loss of decision-making control. Avoidance of thinking about the future or of talking about it helped these participants remain positive and to cope with their loss in cognitive function. This was one of numerous mechanisms which participants WDLA had adopted in response to their cognitive impairment.

Coping mechanisms

Although dementia had a significant impact on the lives of participants WDLA, the majority of them had remained positive and had actively put in place mechanisms to cope. Only two participants, John and Adam, had not implemented such mechanisms; John was in denial about his cognitive impairment and was consumed with grief over the loss of his

wife and found it difficult to imagine any life without her. For Adam, loss of memory had left him feeling helpless and he focused only on the capabilities he had lost. Among the remainder of the participants WDLA many coping mechanisms were identified: behaviour modification strategies, tangible actions, peer support and remaining in the home environment. In addition to avoidance of the future, behaviour modification strategies aimed at helping participants WDLA to remain positive included: minimisation; focusing on existing capabilities; acceptance; and remaining hopeful. The data also identified tangible actions such as the use of memory aids, exercise and peer support to be important mechanisms in helping participants WDLA cope with the loss in functional capacity and the stigma associated with a dementia diagnosis. Remaining in the home environment was also identified as an important mechanism in helping participants cope with loss of memory and maintain their power of agency and their autonomy in their daily lives.

Adaptive behaviour strategies

Minimisation techniques were found to be used by two participants WDLA to help them remain positive and cope with their cognitive impairment. Both Peter and Michael considered there were worse conditions to have and counted themselves fortunate only to have dementia, as Michael explained:

But of course I don't have cancer or whatever. Compared to other disease[s], I think I'm lucky. (Michael, age <80)

Other participants, such as Ann, believed it was important to focus on the present and her existing capabilities rather than on her loss or further future loss of functional capacity.

This focus helped participants remain positive about their current situation, as can be seen in the following excerpt:

as soon as I start to feel sorry for myself and things like that, I think 'I'm still alive, I can still enjoy doing some things. I'm not a danger, only to myself,' then I feel alright again. (Ann, age >80)

For some participants WDLA, coming to terms with their dementia diagnosis was a critical step in coping with their condition. In the early stages following a dementia diagnosis, some participants WDLA, such as Peter and Jane, found they often got anxious and frustrated with their loss in functional capacity, which in turn made their symptoms worse as they were magnified under stress. Peter and Jane both recognised the importance of remaining calm and found that only after gaining acceptance of their condition and focusing on the present did they begin to feel less stressed. Peter explained:

I try very hard not to get too panicky or anything like that or disgusted with myself that I can't do this and that, and I'm able to say to myself I know what the problem is and if I lose my cool, it's only going to get worse. (Peter, age <65)

These participants also recognised that their ability fluctuated and that if they were unable to do something one day, they might be able to do it the next day. Jane was at a stage where she accepted when she could not accomplish something and just delayed taking action till another day, as she explained:

If I can't do it and I know that I can't do it, which I usually do know, you know, what's happening. I don't worry until the next day, you know. (Jane, age <65)

Hope was also a coping mechanism for some other participants WDLA; the hope that one day they might improve and be able to return to past activities or past employment. Although these participants seemed to understand the dementia trajectory, they were not willing to give up hope for the future. An example from Michael is given below:

I don't sit here and cry or anything like this. Absolutely no...I could be the first to get better. (Michael, age <80)

Similarly, Mary and Adam understood that it was not safe to drive, yet both were unwilling to sell their cars as they still held onto the hope that one day they might drive again. These participants WDLA did not appear to lack insight, as they were able to discuss their deterioration at other stages during the interview, but holding on to hope seemed to help these participants cope with their cognitive impairment.

Tangible actions

Participants WDLA had adopted various mechanisms to overcome their loss in functional capacity, such as reading self-help books and memory training books or using memory aids, such as calendars and reminder signs around the home. Exercise was also identified as an important coping mechanism for three of the younger participants (Peter, Jane and Michael). Exercise made them feel as if they could take some positive action in managing their condition. Jane explained:

I go to exercises Mondays, every Monday, and I walk with friends on the Thursday...I know it's good for my brain and it's good for everything actually, on my body. (Jane, age <65)

For Peter it was important to him that he could go walking without restrictions, and unlike two of the other participants described earlier he did not fear getting lost. He acknowledged that he had gotten lost on occasion, but to reduce the risk of harm he wore a name tag around his neck which provided emergency contact numbers. Peter stated:

I want to be able to just get out and about and things like walking my way without anyone with me. If I get lost, well you've just got to laugh about it. (Peter, age <65)

These tangible actions made people WDLA feel better while also providing them with a belief that they could still exert a level of control over their condition.

Peer support

Peer support emerged as a significant mechanism in helping some participants WDLA (Peter, Mary and Jane) cope with their cognitive loss. These three participants regularly attended two different peer support groups and found it a great source of enjoyment and comfort to be surrounded by people who shared their condition and understood the challenges faced. As previously discussed, members of this group were often concerned with how others perceived them, yet amongst peers they felt comfortable being themselves and they did not feel the need to hide their deficits. An example from Jane:

I suppose, that's the only place I can go to where I can just, I don't have to be anybody else. Just who I am basically, or who I am now. (Jane, age <65)

Some of these participants kept in regular contact outside the formal structure of the group and found that they could lean on each other for support and often became integrated into each other's social worlds. Three participants WDLA had developed romantic relationships with other people with dementia. Peter explained:

She's sort of been through what I've gone through. Maybe she's had it probably a little harder than me but I think it's good because apart from the situation, romance sort of strengthens you. You've got someone who you can be close to and know that they're going to be half wacko one day. Don't know what's going on. So that's good. (Peter, age <65)

Although these participants found benefit in being in a relationship with a person who shared the same condition, they also acknowledged that it made it difficult to sustain these relationships; such pressures led to two of the relationships ending.

Peer support groups also provided participants WDLA with an opportunity to socialise, attend activities and have fun together. Prior to attending a peer support group, Mary acknowledged that she had become withdrawn and had been inclined to give up on her interests. Since attending the group, Mary believed that her quality of life had increased

as she now laughed more, socialised more and had developed a renewed interest in previous activities. Mary stated:

Somehow I want to keep going up there now. I can because I'm feeling so much better, because I was a cot case. (Mary, age >80)

Peer support also provided an environment where these participants felt comfortable sharing their mistakes without being concerned about how others would judge them. Peter spoke about a group called '*Let's Get Lost*', the purpose of which was to encourage its members to see humour in their mistakes rather than fearing memory loss. The data from this study showed that participants WDLA who had peer support rated their '*ability to have fun*' as 'good' in the QOL-AD questionnaire, while those without peer support rated their '*ability to have fun*' as 'poor'. There is a possibility that peer support groups may help increase a person WDLA's ability to have fun or it may be that people more likely to have fun are more likely to access peer support groups.

In spite of the benefits, peer support groups were not suited to all participants WDLA. For example, Michael, on attending a peer support group, found that the majority of the participants were female and also that they were further along the dementia trajectory; he described them as '*gaga*'. This experience reminded him of his future, which he preferred not to think about, and he had chosen not to attend again. These results suggest that it is important that peer support groups cater for both genders and for the different stages in the dementia trajectory if they are to meet the needs of all people WDLA.

Home environment

All people WDLA participating in this study wanted to remain living at home for as long as possible as they believed that their home afforded them a level of control over their changing world and for them it was also the best place to cope with fading memory. Ann explained:

I would like to think that I'm being sensible, not stupid, because I want to stay in my home. I'm not hurting anyone. (Ann, age >80)

Owning their home was particularly important for these participants WDLA as they were of the view that ownership prevented them from being placed into residential care against their wishes; as Jane said:

This is my house. My unit. So no one's going to kick me out. (Jane, age <65)

Although, participants were losing power of agency and power to participate in the decision-making process, their home enabled them to continue to exert a level of agency over other aspects of their daily living, such as choosing how to spend their day. Being able to exert agency was extremely important to all people WDLA in this study, and participants feared that a move away from their home would result in a loss of agency and autonomy. Mary explained:

I mean why would I want anything else? I mean you can still have friends, and you can still have company, but I can listen to whatever music I like to listen to. (Mary, age >80)

The data suggested that home contents were also important to some participants WDLA as these not only provided enjoyment but also formed part of the person's identity. These participants feared that if they had to give up their home contents they would also lose part of themselves. Again, Mary provided an example of this:

I don't want to go into a little place. I've collected all these books. There's books all through the house, on the bed, under the bed, in everywhere you know. Books. And that's me. (Mary, age >80)

Home contents also represented a person's life history and served as a reminder of past events, and some participants WDLA were concerned that if they were not surrounded by these things, their memories would fade. John for example, believed his home was too big

for him since the passing of his wife but although he struggled to maintain it, he was reluctant to move to a smaller place for fear that a move away might cause his memories of his wife to fade. John stated:

*I've tried several times thinking about it but I just put it in the too hard basket.
(John, age <80)*

John's fear over his loss of memory prevented him from taking any action to find a smaller, more manageable living space.

For other participants WDLA, the routine of their home and of having a familiar environment helped them cope with loss of memory; these participants feared that they would not be able to manage if they moved to an unfamiliar place. For example, Mary struggled at times to remember where she put things, but in her home she had set routines and knew that there were only a small number of places where she could put things. Therefore, when Mary misplaced something she just checked all of these places. Mary believed it would be too traumatic trying to orientate herself and her possessions in an unfamiliar environment, as presented below:

*I can't find anything now, I mean what would I do? It would be a nightmare.
Absolute nightmare, and I can't do it. (Mary, age >80)*

Participants WDLA were asked during the interview if they would consider residential care as an alternative living space, but none of the participants wanted to leave their own home unless they had to. As previously discussed, the home enabled these participants to exert a level of agency and autonomy over their lives and for this reason they were reluctant to leave it. A move away was perceived as relinquishing control and giving up on life, while a transition to residential care was seen only as a place to go in the final stages of life. As John explained:

...you go there to die that one, what would I do? They go in and they never come out do they? (John, age <80)

Most participants WDLA recognised that they would eventually need to move from their home into residential care but as long as they had a level of capacity they wanted to remain in their home. Sally provided an example below:

I'm quite capable of doing things for myself. I'm not going to go into a nursing home unless I really have to... Why should you give it up if you feel you're capable of doing something for yourself? (Sally, age>80)

Once they no longer had capacity, these participants WDLA were of the view that they would be accepting of a move to residential care. Although participants WDLA acknowledged there were risks associated with living alone with dementia, some appeared to be more fearful of being placed into residential care than of any such risk. For example Ann was of the view that:

It's the fact that if I die in the house, I'm going to die sooner or later... So why should they all think, and I'm sure they all think, she should be put away. So I've had my say. I'm not going to be put away. (Ann, age>80)

Similar to the findings on decision-making capacity, Ann was also concerned that others might judge that she no longer had capacity to remain living at home and that they might place her in residential care against her wishes. Ann explained:

I've done some funny things. Occasionally, without even thinking I've done the wrong thing. But I've got to go back and apologise... But is that any reason to put me into a home or something? I don't think so. I think that any mistakes I make, I usually find out before anyone else, and apologise. I don't know how elderly people go, or how they're treated, but sometimes I think it's very unfair. (Ann, age >80)

In order to prolong the length of time they could remain living at home, many of the participants WDLA had adopted strategies or made adaptations aimed at minimising their

risk of harm or at alleviating the safety concerns of others. For example, two of the nine people WDLA still cooked for themselves (Jane and Michael) and Jane had chosen to cook only in the oven to minimise risk. Jane explained:

I tend to cook things that are easy for me to cook anyway because that's usually, you know...I put everything in the oven basically rather than on the top of the stove. (Jane, age <65)

Ann had also taken steps to minimise her risk of harm and to alleviate the concerns of others. Ann had made a promise to avoid using the rear steps of her home as they had a tendency to be slippery. She recalled:

And of course I went to walk down the back steps the other day for something, not even thinking, and I got to the second step and I thought 'oh shit, I'm not allowed to go down the back steps'. I quietly turned around, came back and came around the driveway. (Ann, age >80)

Ann had taken further measures to minimise the risk of harm associated with her actions and those of others by wearing an alarm activator on a chain around her neck. Ann interrupted the interview for a short period of time when she realised she had forgotten to put it on and wanted to get it. As she explained:

If you don't mind, I've got to put something on. Not clothes. My buzzer. It's sitting there very calmly on the kitchen table. Not that I think anyone's going to do anything, but I've just suddenly realised I didn't have it on. And that really is not a very good idea. (Ann, age >80)

All these measures were aimed at increasing the amount of time these people WDLA were able to remain living at home independently. Two of the other participants, Jane and Peter, were conscious that due to their condition and because they lived alone, they may lack insight and overestimate their capabilities. To overcome this limitation, both participants spoke of using a third party to regularly assess their ability to perform certain

tasks. Peter used the case manager assigned to him by the health service, while Jane relied on her friends to provide an independent assessment of their capabilities. Jane explained:

But you know I keep an eye on things to make sure everything's alright, and I get other people to check, you know, make sure I'm doing the right thing, that sort of thing. And I've been okay so far. But if I got to – when that time comes I have no trouble with handing things back. You know, I wouldn't try to do what I can't do. (Jane, age <65)

These measures reassured Peter and Jane that they were not putting themselves or others at risk due to their cognitive impairment.

The results showed that these participants WDLA wanted to remain living at home for as long as possible because set routines, a familiar environment and the contents of the home were important mechanisms in coping with dementia. The home was also a place where participants WDLA could continue to exert power of agency and a level of autonomy over their lives at a time when they were experiencing many other losses. Participants WDLA had made various adaptations to their previous way of living to maximise the amount of time they were able to remain living there.

Conclusion

The results presented in this chapter demonstrated that participants with mild to moderate dementia living alone were able to participate in research and provide consistent responses on their experiences of living with a cognitive impairment. The QOL-AD data demonstrated that the majority of participants WDLA rated their quality of life high, with 'living situation' and 'closest relationship' receiving the highest scores. The data also indicated that a low score for 'ability to do things for fun' may be an indicator of social isolation for people WDLA. The QOL-AD results showed that the advocates participating in this study had a good understanding of how their clients, that is people WDLA, perceived their QOL, as the scores were similar for the majority of the 13 items.

The data gathered from the semi-structured interviews showed that participants WDLA had insight into their changing condition and were aware that they were losing functional capacity and the power to participate in the decision-making process. Loss in functional capacity had a significant impact on the lives of people WDLA, resulting in loss of power of agency and diminished self-esteem, which in turn led to decreased social interactions and increased risk of harm, social isolation and dependency. In addition, almost all of the participants WDLA had experienced marginalisation in the decision-making process, largely due to the actions of well-meaning family and friends which reduced the agentic power of participants WDLA. Many participants WDLA feared further deterioration in power of agency and autonomy, and tried to avoid thinking about their future.

Although, participants WDLA were losing power of agency, the majority of them were also exerting agency to adopt mechanisms to cope with dementia, such as behaviour modification strategies, tangible actions, peer support and remaining in the home environment. Behaviour modification strategies, tangible actions and peer support were predominantly aimed at helping participants WDLA to cope with their loss in functional capacity and to remain positive, while remaining in the home environment played a major role in facilitating the agency of these participants. An interpretation of these findings and their theoretical implications are provided in Chapter Six.

Chapter Five presents the data on advocacy and the dementia advocate role and discusses the experiences of people WDLA, advocates, and healthcare professionals with the dementia advocacy service in Tasmania.

Chapter 5: Dementia Advocacy

Introduction

In Tasmania, the dementia advocacy service, provided by ATI, aims to support people WDLA ‘to make their own decisions and continue to manage their lives so that they can remain living successfully in the community for as long as possible’ (Advocacy Tasmania 2010). To achieve this aim the dementia advocate services endeavour to implement a ‘proactive’ approach where people WDLA are referred early in the dementia trajectory so that advocates can work with them to plan for the future, establishing processes such as enduring guardianship and power of attorney, while they still have capacity. This is a novel approach that ATI have adopted since working with people WDLA which is different from the ‘issue-based’ advocacy used for other client groups, under which advocate support is called upon for a specific issue or decision.

This chapter focuses on the findings on the dementia advocacy service using data gathered from three participant groups: clients, advocates and healthcare professionals. Nine clients who had used advocacy services in the six months prior to data collection participated in the study and of these six participants WDLA were able to recall specific examples of advocacy involvement. Twenty-one healthcare professionals (15 female and six male) provided data, either through focus groups or individual interviews, on their experiences of interacting with the advocacy service. As discussed in Chapter Three, to protect healthcare professionals’ identities, quotes make reference only to membership in one of the four allocated groups: assessment; community care; home and social support; or medical professional. The four dementia advocates, working throughout Tasmania, were also interviewed to ascertain their views of the service and the effectiveness of

advocacy in facilitating participation of people WDLA. Due to the sensitivity of the data collected, and to protect advocates' identities, the same pseudonym, 'Paula', is used for all advocate quotes.

This chapter begins by reporting on the benefits of advocacy involvement for people WDLA and then proceeds to discuss the major factors impinging on the effectiveness of the advocacy service which emerged from the data.

Benefits of advocacy

The three participant groups (clients, advocates and healthcare professionals) identified many advantages of advocacy involvement for people WDLA, which can be classified into three main benefits: protected people WDLAs' right to participate in decision-making; promoted their power of agency; and assisted them to remain at home. Each of these themes is discussed in detail below.

Protected people WDLAs' right to participate in decision-making

Much of advocate involvement was focused on protecting the person WDLA's right to participate in the decision-making process. This was achieved either through ensuring that the voice of the person was heard and restoring their agentic power, or by enhancing their communication and facilitating their power of agency. It was acknowledged by advocates and some healthcare professionals that the wishes of people WDLAs were frequently ignored in decision-making forums and that people WDLA can be forced into decisions against their wishes, as exemplified below:

I'd like to think it's not the case, but people can be, in a guardianship context, people can be railroaded. Like the big wheels can sort of turn and churn people out the other end. [Medical professional interviewee]

The presence of an advocate in these decision-making forums acted to restore agentic power to people WDLA by reminding healthcare professionals of the importance of hearing the voice of the person WDLA and ensuring their right to participate in decisions was respected. Formal meetings in which key decisions were made about their life and their living situation could be very intimidating experiences for the person WDLA, especially if they also had communication deficits. Providing advocate support leading up to and during these meetings assisted in reducing the underlying power differentials between the person WDLA and healthcare professionals, as shown below:

...if someone's got difficulty communicating they straight away are in an undignified position, ... so to have someone who is outside of the system for them, essentially empowers them, it can be fantastic, because it's such a disempowering thing to walk into an institution. [Member of Community Care Group]

Advocates also acted to provide a 'check and balance' [Medical professional interviewee] on the actual decision-making process which served to minimise sociocultural bias.

Advocates were found to be particularly beneficial in protecting the right of people WDLA to participate during conflict situations, either with family members or service providers. In such circumstances advocates were able to mediate between the parties while still ensuring the rights and wishes of the person WDLA were kept to the forefront, as described here:

...an advocate can be really good in teasing through all the information, and misinformation, and you know, ensuring the client keeps the most appropriate care. [Member of Assessment Group]

Referral to the advocacy service not only protected the rights of people WDLA, it also provided healthcare professionals with some protection from false accusations or

miscommunications. Advocates, at times, assisted in providing an independent and balanced perspective, helped to dissipate tensions and alleviated any underlying concerns while also protecting the person WDLA's right to participate in the decision-making process. An example was given by a member of the Assessment Group:

I invited an advocate for him, so he would have someone to express his opinions to, and who would work for him, because I felt that that was fair to do that, and to me it was a protection of me, as well as the protection for him. [Member of Assessment Group]

Healthcare professionals acknowledged that at times they may be torn between what is right for the person WDLA and what is right for their organisation, and the use of an independent advocacy service avoided this tension, as described below:

...sometimes we get caught up in our role, or caught up in our duties and responsibilities, and shaped by that, and having an external source means they're not shaped by that. [Member of Community Care Group]

The independence of the advocacy service was an important component in protecting people WDLAs' right to participate and have their voices heard. An independent service can ensure that any vested interests of family members or any cultural biases of healthcare professionals and their organisations are mitigated and that the wishes of the person WDLA remain central in the decision-making process.

Enhancing people WDLAs' communication also emerged as an important means by which advocates could protect the right of people WDLA to participate and facilitate their power of agency. However, advocates acknowledged that this process can take '*a lot of time and commitment and understanding of them as a person and their values*' [Paula] before their wishes are ascertained. Healthcare professionals recognised that their organisation lacked the time necessary to support people WDLA in overcoming major communication deficits, as demonstrated below:

...she really made a difference, and I didn't know what else to do, and I was really glad I referred to her. [Member of Assessment Group]

Moreover, client-directed service providers participating in this study recognised that they may lack the communication skills and time necessary to obtain direction from people WDLA from culturally and linguistically diverse (CALD) backgrounds. In these circumstances, professionals found great benefit for both the person WDLA and their organisation in being able to refer the client to the advocacy service:

Advocates can really do a great job and we call them in where we think that we might not be able to converse with those [CALD] people on an equal basis. [Member of Home and Social Support Group]

Two important factors were identified which contributed to increased levels of communication between people WDLA and advocates: style of communication and trust. Participants WDLA found that the style of communication, including language, used by advocates was easy to understand and did not make people WDLA feel intimidated, as Mary described:

Well I think if you've got someone to talk to, like Paula, who's not overpowering with knowledge that can make people with little knowledge to feel inferior, and idiotic. [Mary, age>80]

Furthermore, participants WDLA felt respected by the way in which advocates communicated with them, while two of them referred to the advocate as a 'human being' [Paul] or as being 'very humanitarian' [Ann], which they considered few people were towards them. Additionally, participants WDLA appeared to trust their advocate and felt comfortable to discuss their mistakes without fear of ridicule or reprisal, as Ann explained:

It's heaven. To know that she won't laugh at you. ...she won't laugh at your effort at whatever it is. [Ann, age>80]

These results suggest that independence, time, communication style and trust are important elements of the advocates' interactions and may be important aspects of protecting the right of people WDLA to participate in the decision-making process.

Promoted power of agency of people WDLA

People WDLA were losing cognitive function and their ability to make complex decisions and this loss induced feelings of anxiety: *'things don't get resolved, they just sort of go round in circles'* [Paula]. Data from advocates and participants WDLA suggested that the support of an advocate could reduce anxiety and increase the person WDLA's power of agency. Paula believed that:

By taking that stress away, their [people WDLA] confidence to do what they need to do is a lot better. [Paula]

Some participants WDLA found that the early stages of the disease, particularly following a dementia diagnosis, were very overwhelming and that referral to the advocate during this period reduced their anxiety. Jane, for example, described her advocate, recalling their first meeting, as *'just like a fairy Godmother really'*, as she provided her with an avenue to discuss her fears and concerns following her diagnosis. Jane also benefited from leaning on someone for support, such as the advocate, who was not emotionally involved, and this support gave her the confidence to exert power of agency. For others, unfamiliar symptoms led to increased anxiety over their future and the advocate provided a degree of reassurance and comfort to people WDLA during this time, as Mary explained:

The doctors they didn't know what to do with me. They told me that. They really didn't know what they were going to do. And then you [the advocate] turned up. [Mary, age>80]

It was not always necessary for the advocate to be directly involved; for some participants WDLA knowing there was ‘*someone that cares*’ [Ann] whom they could call upon if needed was enough to reduce their levels of anxiety.

Through a relationship with the advocate, participants WDLA developed the confidence to take action. By spending time with the person WDLA, the advocate was able to facilitate their power of agency by working through their issues, providing them with relevant information and supporting them in completing any associated paperwork. An example of this:

I guess I did a lot of the hack work for her of finding out the information and we sat down and filled in the forms together. And then she took them in as though she'd done it all. And she was feeling really confident. And I asked her if she wanted me to come with her, and she said, 'No, I'll be all right.' And I thought, oh, that's so important. She doesn't need me holding her hand. [Paula]

Advocates felt that the more a person WDLA could achieve themselves the better they would feel, although advocates acknowledged a substantial amount of time may be needed in order to help the person WDLA work through information and take action. Some healthcare professionals expressed the view that they do not have the resources to support people WDLA in the community who require time, as the quote below shows:

There's so many people out there alone, who need someone in there battling for them basically, and taking along with every step of the way, because we see them for a short period. [Member of Assessment Group]

By spending time with the person WDLA, the advocate felt they relieved anxiety, empowered the person WDLA and helped them come to terms with a diagnosis of dementia. Spending time with the person WDLA to discuss their fears and supporting them in the actions they wanted to make appeared to increase their belief in their own power of agency.

Assisted people WDLA to remain at home

Analysis of the data identified four ways in which advocates provided tangible support to people WDLA which contributed to their safety and their ability to remain living at home. They: accessed other support services; protected against financial abuse; attended medical appointments, and; assisted with financial responsibilities.

Accessed other support services

Advocate involvement assisted people WDLA to access two forms of support, which included more formal services, such as home support, and less formal services, such as social support. Many healthcare professionals felt that without advocacy involvement, people WDLA would not have received these two forms of support and that the acceptance of these services enabled people WDLA to remain living longer in the community, as shown in the example below:

In most cases it's [advocacy] assisted people to stay engaged socially, stay living in the community for longer than they would probably have been living in the community. So that kept them out of aged care basically. [Member of Home & Social Support Group]

As mentioned in Chapter One, living alone with dementia is often a major predictor of no service use (Webber, Fox & Burnette 1994). Data from this study suggested that through the establishment of a trusting relationship, advocates were able to influence people WDLA to accept the support of others and also to help them work through the various options available to them. An example of the importance of this relationship is provided in the following excerpt:

...this person was very resistive to services, and was, you know, problems were escalating, and there didn't seem to be any way for anybody to get in the door basically, and advocacy were able to sort of approach the person, and, you know, form a relationship, and continue on. [Member of Assessment Group]

The trusting relationship between the person WDLA and the advocate was particularly beneficial to service providers and people WDLA in circumstances where there was no family support. Service providers require written consent from a person WDLA before services can be provided and this was difficult to obtain in circumstances where the person was frail or lacked capacity and had no family member to sign on their behalf. Advocacy involvement appeared to facilitate this process by signing on behalf of the person WDLA and representing their needs. Some healthcare professionals also acknowledged that people WDLA get ‘*more mileage from the services that are available*’ [Medical professional interviewee] when advocates are involved. Therefore, the trusting relationship between the person WDLA and the advocate not only had the potential to increase service use, but it also ensured maximum benefit was obtained from available services.

In addition to facilitating access to formal support services, some advocates perceived part of their role as being to connect those who are at risk of social isolation to social supports, such as peer support. This is significant given that the previous chapter has shown that people WDLA experienced a narrowing of their social worlds. Once a trusting relationship was established, advocates were able to encourage people WDLA to use social support services. There was a belief amongst some healthcare professionals that without advocate involvement, the person with dementia would not have accessed social support groups, as described below:

...what I have witnessed during all these years is that they wouldn't be there without an advocate... [Member of Home and Social Support Group]

This trusting relationship enabled the advocate to positively influence the actions of people WDLA. One advocate took it upon herself to organise informal gatherings of people

WDLA, of similar ages and at comparable stages in the dementia trajectory, demonstrating how important they believed this type of peer support to be. As Jane explained:

[the advocate] would round a few of us up and we'd go out somewhere for lunch and do something nice [so that] when they go out they feel comfortable and all that sort of thing. [Jane, age<65]

The advocate's purpose in building a peer support network was to help people WDLA cope with their condition and to reduce the risk of social isolation. Although Chapter Two has shown that people WDLA were at greater risk of social isolation, there were differences of opinion between advocates as to whether assisting people WDLA to build peer support networks fell under the scope of advocacy. Therefore, not all advocates were providing this service to people WDLA.

Protected against financial abuse

All participant groups were of the view that advocates played a significant role in either preventing or ending the financial abuse of people WDLA and several examples were provided to support this claim. A member of the Home and Social Support Group provided an example where advocacy involvement prevented a person WDLA from being placed in a financially vulnerable position, as shown in the following excerpt:

...the advocate was involved in stopping him [person WDLA] giving power of attorney to some maybe inappropriate people. [Member of Home and Social Support Group]

In circumstances where there was concern over financial mismanagement, advocacy involvement appeared to achieve cessation of the abuse through either direct or indirect action. Examples of this were provided by two participants WDLA, Ann and Adam, which were also corroborated by their advocates. In Ann's case, she had lost trust in the holder of her power of attorney and the advocate helped support her in her decision to remove this person and regain control over her finances. In Adam's case, the mere

involvement of the advocate was sufficient to stop the financial abuse by a family member. In spite of the abuse stopping, Adam wanted the advocate to remain a presence in his life to act as a deterrent to other potential abusers. Advocate involvement provided these people WDLA with the necessary tools and support to enable them to address the financial abuse experienced.

The data analysis identified two reasons why financial abuse of people WDLA may remain undetected: limited close relationships and loss of memory. Advocates explained that their clients WDLA were often reluctant to confront their abuser for fear of losing this connection as many of them had few close relationships. Often protecting these relationships appeared to be more important than the financial loss experienced. In these circumstances advocates believed that utmost care must be taken to avoid damaging the relationship if people WDLA were to agree to any action being taken. Advocates were also of the view that financial abuse often remained undetected as people WDLA frequently blamed any financial anomalies on their loss of memory. Advocates perceived that their role was to help people WDLA uncover the truth of a situation, as described in the example below:

*...they get a bit confused that maybe I was the one that lost my money or maybe I didn't pay my bills and that kind of thing and, of course, then someone who's willing to take advantage of them will play on that and it's just a matter of 'let's get your bank statements and what have you and we'll go through them and then if you like we'll have a chat to the person and see where things have gone'.
[Paula]*

These results showed how advocate involvement can support the person WDLA to take action against financial abuse and can also decrease the person WDLA's vulnerability to it.

Attended medical appointments

Analysis of the data found that advocate involvement in medical settings can help achieve better outcomes for people WDLA and for medical professionals. Advocates provided people WDLA with the opportunity to discuss concerns prior to the medical appointment, acted as a support during the consultation, and offered reminders post appointment, as described by Paula below:

But preparing [helping] them prepare for the meeting, attend the meeting, check that they have asked the things that they decided beforehand they wanted to ask, checked that they've understood what it is that the doctors are recommending, and then reinforce those things after the meeting. [Paula]

In supporting the person WDLA, the advocate facilitated a more useful patient experience and reminded people WDLA of agreed outcomes.

In circumstances where there was no family support, medical professionals also found benefit in having an advocate present. In these situations, advocates were able to provide medical professionals with insights into a person WDLA's history and current living situation. This process enabled medical professionals to achieve a balance between understanding the actual care needs of the person WDLA and the wishes of the person WDLA, as described in the following excerpt:

So seeing them with someone who knows them and has their head around the issue and has a good understanding of what this person's wishes are, that's a good thing. [Medical professional interviewee]

In summary, advocate involvement during medical appointments facilitated greater understanding and achieved a more positive outcome for both patient and medical professional.

Assisted with financial responsibilities

Advocacy involvement also assisted people WDLA with financial responsibilities and these interventions helped prevent them from falling into arrears or losing possession of their home. In one instance, for example, a participant WDLA had '*forgotten to pay his mortgage for six months and the bank were about to foreclose*' [Paula] but with the assistance of the advocate an agreement was reached with the bank which enabled the person WDLA to keep their home. In a second instance, the advocate was helping one of the other participants WDLA to set up direct debits for payment of utility bills as described below:

And also she wants me to put a few dollars into a direct debit. They won't do it with my bankbook. So I have to keep running to the post office, like last week she came, and I had to get to the bank to get the money to pay the electricity bill, otherwise it was \$200 they would have charged me if I had have been a day out, you see. [Mary, age>80]

These actions not only helped the person WDLA meet their financial obligations, they also reduced their reliance on others and decreased anxiety about late payment. This support helped to reduce complexity and to suggest manageable solutions which allowed people WDLA to remain living at home. Advocate assistance in managing these financial responsibilities may be particularly pertinent to this cohort as many of the clients WDLA of the advocacy service had limited family support.

Factors impinging on advocacy effectiveness

In spite of the many benefits of advocacy involvement highlighted above, advocates declared that referrals of people WDLA to the service remained low. In addition, healthcare professionals expressed a mixture of positive and negative experiences of the advocacy service and conveyed some reluctance to refer people WDLA to the service. Analysis of the data identified five factors which impinged on the effectiveness of

advocacy in facilitating the agency of people WDLA, these were that: lack of understanding of advocacy services limited referrals; perceptions of capacity influenced expectations of advocates; perspectives on capacity and risk influenced agency; blurred boundaries risked agency, and; structural and interactional challenges limited opportunity. Each of these factors is discussed below.

Lack of understanding of advocacy services limited referrals

Analysis of the data identified that there was a lack of understanding of advocacy and the advocate role by both healthcare professionals and people WDLA which contributed to low use of dementia advocacy services. Most healthcare professionals acknowledged that they ‘*don’t know entirely what they [advocates] do*’ [Medical Professional interviewee], and there was a lack of clarity in the distinction between their own role and that of the advocate. One of the difficulties contributing to low referrals was that healthcare professionals believed that advocacy was part of their own role and did not see the necessity to refer to another organisation. As a result, many healthcare professionals only considered referring people WDLA to the advocacy service in particular circumstances, such as suspected abuse or family conflict. For example:

...we involve the more formal advocacy service when there’s probably a little bit more conflict, perhaps, involved or something like that that we can’t manage ourselves certainly. [Member of Home and Social Support Group]

A further circumstance in which healthcare professionals acknowledged that they might make referrals was when they were unable to resolve an issue with a person WDLA, but this was considered a rare occurrence. An example from the Assessment Group is provided below:

...so it’s when you maybe get stuck, and you feel maybe this is where an advocate might be needed, because you’re not able to move forward with that issue. [Member of Assessment Group]

The decision by healthcare professionals to involve advocates only in these circumstances limits the opportunity of people WDLA to avail themselves of the benefits of advocacy in facilitating participation. General Practitioners (GPs) appeared least likely to refer to the advocacy service, as shown below:

I've never actually heard of a GP actually referring... [Member of Assessment Group]

Consistent with other healthcare professionals, the GP interviewed in this study was of the view that GPs generally see *themselves* as the patient's advocate and therefore do not see the necessity of involving an external service. Furthermore, he explained that GPs were '*trained to be a bit self-sufficient*' [Medical Professional interviewee] and that this further contributed to their reluctance to involve others. Advocates, on the other hand, attributed the dearth of GP referrals to the GPs' lack of understanding of the dementia advocacy service, but found it difficult to access GPs to inform them about the service. Lack of GP referrals is likely to represent many missed opportunities for advocacy to support people WDLA, as members of the assessment group explained that GPs were often the only healthcare professionals interacting with people WDLA in the early stages of the disease.

A further difficulty evident from the data was the lack of distinction between some healthcare professional roles, such as of case manager and of advocate. Many healthcare professionals believed that the case manager role incorporated an advocacy dimension and considered independent advocates to be unnecessary if a person WDLA had been assigned a case manager. This confusion was expressed in a response to a question about case managers:

I really do see it as much the same. Maybe I'm wrong. [Medical professional interviewee]

Moreover, several healthcare professionals considered that a case manager was best placed to support the person WDLA due to their knowledge of the health service and their understanding of the limited resources available to support people WDLA, thus ensuring that service expectations from people WDLA were not unrealistic. There was a belief amongst these healthcare professionals that there were not enough case management resources available, and they preferred to see further investment in the expansion of case management rather than the advocacy service. This lack of understanding and clarity of the differences between the advocate role and those of other healthcare professionals had a negative impact on the number of people WDLA being referred to the advocacy service.

There was also a marked lack of understanding amongst the majority of healthcare professionals of the 'proactive' approach used by the advocacy service. Although future planning for people WDLA was a fundamental aspect of this service, the majority of healthcare professionals were unaware that advocates provided this support, believing the service to be issue-based only. The Home and Social Support Group suggested that the number of referrals would have been much higher had they been aware of this service, as had they seen an important unmet need to support people WDLA with the paperwork associated with the transfer of a Power of Attorney and the appointment of an Enduring Guardian. The few healthcare professionals who were aware of the future planning aspect of the advocacy role were supportive, as in the example below:

I think that's when advocacy can work really well, when there isn't an issue as such, but just planning to do it and firm up and yeah, help that person express what they want for the future, is one situation where it's working really well I think. [Member of Community Care Group]

Lack of understanding of advocacy services and poor distinction between the advocate role and healthcare professionals' roles contributed to the infrequency of decisions by healthcare professionals to refer people WDLA to the advocacy service. Some healthcare professionals suggested that the advocacy service should provide training on their role to the different organisations and individuals involved in the care of, and provision of services to, people WDLA.

Furthermore, it appeared that the terms 'advocate' and 'advocacy' were also not clearly understood by people WDLA, which contributed to reluctance by healthcare professionals to discuss advocacy with people WDLA. Some healthcare professionals believed that for many people WDLA, particularly those from non-English speaking backgrounds, the term 'advocacy' was associated with lawyers or some other official or legal process, which people WDLA were reluctant to be involved in, as exemplified below:

I certainly know that I have to sometimes couch advocacy in different terms with some clients, because a lot of the elderly people I see are quite passive by nature, and sometimes the word advocacy they see as some sort of agitation.
[Member of Assessment Group]

Other healthcare professionals found that when the term 'advocacy' was mentioned people WDLA formed one of two perspectives, the first of which was '*I'm in trouble*' [Member of Community Care Group], and the second of which was that advocacy was '*some sort of puzzling new service you want them involved with for some unknown reason*' [Member of Community Care Group]. Healthcare professionals needed to spend time with the person WDLA to explain the advocate role and this may be challenging in circumstances where there was also a common misunderstanding of the role, or a reluctance to engage with the service. More importantly, people WDLA were often reluctant to involve advocates as they feared this might lead to them being placed in residential care against their wishes, as evidenced by the following excerpt:

Particularly frail aged people living independently in the home and you start to talk about advocacy for them it's residential care too, because in their mind a lot of things will happen in the future, all this advocacy involvement, what feedback I get from a few clients where they're saying 'I don't want to get anyone involved because – next thing, I'll be in a nursing home'. [Member of Home and Social Support Group]

These data suggested that the lack of understanding of advocacy and fear of losing the ability to remain at home impinged on the ability of people WDLA to obtain the support and potential benefits of advocacy.

Perceptions of capacity influenced expectations of advocates

Expectations of advocates differed between healthcare professionals and advocates and these differences created tensions in the relationship between them, resulting in reluctance to refer people WDLA to the advocacy service. Expectations of advocates were linked to the healthcare professionals' perspective on capacity of people WDLA to participate in the decision-making process. These perspectives shaped the expectations of the dementia advocate role. Three diverse perspectives were identified in this study which were: that people WDLA have not the capacity to make decisions; that the majority of people WDLA have decision-making capacity; and thirdly, that people WDLA should be allowed to make decisions as long as they are informed, in their best interest and safe.

A small number of healthcare professionals shared the first perspective that people with dementia lack judgement, insight and reasoning, and therefore should not be allowed to make decisions. These professionals expected dementia advocates to force the person WDLA to accept services and to identify a person WDLA's needs based on an expert opinion rather than on the wishes they conveyed. One professional felt that a person WDLA's wish to remain at home was irrelevant if there was no family available or willing to support them, as shown in the following example:

It's interesting that people say 'I don't want to go to a nursing home' or whatever it is, but that doesn't really enter into it too much when you know that the family can't do it any more or if there isn't a family you know they really need it. [Medical professional interviewee]

Healthcare professionals who shared this perspective believed that dementia advocates were not meeting their expectations and perceived the service negatively when advocates represented the wishes of the person WDLA. Moreover, healthcare professionals who shared this perspective discounted the agency of people WDLA and marginalised them in the decision-making process.

Advocates held the second perspective; they believed that the majority of people WDLA have the capacity to make their own decisions. They saw their role as helping people WDLA express their wishes, as reflected in the dementia advocacy service motto of 'helping you to stay in control' (Advocacy Tasmania 2010). This second perspective was quite different from the first. Paula explained that:

If somebody actually needs us to do the speaking, they brief us and we speak on their behalf, then that's what we should be doing. So that continuum of advocacy so that we are not taking away, taking power away from the person. [Paula]

This perspective identified the person WDLA as possessing agency and perceived that their role was to support a person WDLA to exert their power of agency in the decision-making process.

The majority of healthcare professionals held the third perspective that people WDLA should be allowed to make their own decisions as long as they were informed, in their best interest and safe. These healthcare professionals felt that the role of the advocate was to help people WDLA come to an informed decision by exploring all options with them, yet they were of the opinion that advocates did not always do so as shown below:

...there was no evidence that there was any attempt made to actually sit with that person and say, 'Is this the [only option] – [or] here are the potential other outcomes that I know in the system'. [Member of Home and Social Support Group]

They were also of the view that advocates were not setting realistic expectations for people WDLA and were incorrectly advising them of service entitlements. Healthcare professionals found that these actions had led to difficulties in their relationship with people WDLA when service providers were unable to deliver the expected services. Additionally, it had contributed to relationship tensions between healthcare professionals and advocates as demonstrated below:

But if an advocate gives an unrealistic expectation as has happened the person's saying, 'Well, you know, you should be getting X', right, fight the world stuff. ... So the advocate's only set up for disappointment, for the advocate to be angrier and therefore more difficult to deal with next time, for the person to be dissatisfied that their needs are not fully met. [Member of Home and Social Support Group]

Advocates, on the other hand, believed that they were providing realistic options to people WDLA but acknowledged that these discussions were normally conducted in the privacy of the person WDLA's home. In a public forum, they perceived that their role was to represent the wishes of the person WDLA, even if unrealistic, and that this may have led to some of the misunderstandings between healthcare professionals and advocates.

Underpinning these perspectives were distinct priorities amongst healthcare professionals and advocates: for the majority of healthcare professionals the safety of people WDLA was their main priority, while for advocates, and a small number of healthcare professionals, protecting the right of people WDLA to make their own decisions was their main concern. These priorities influenced the perspectives of healthcare professionals and advocates on the involvement of people WDLA in the decision-making process.

Healthcare professionals, who prioritised safety, supported the view that people WDLA should be allowed to make their own decisions and exert their power of agency as long as their safety was not compromised, as shown in the example below:

That is the big issue isn't it, and that would probably be the overriding thing, is how safe are they... [Member of Assessment Group]

The rights-based approach taken by advocates and a minority of healthcare professionals did not judge the merits of a decision but protected the right of people WDLA to make a decision, even a poor one. This approach was driven by a belief that the person WDLA has a right to choose their way of living and should also have the right to make mistakes, as is afforded to all others in society. As a member of the Assessment Group put it:

...this is really what they're [advocates] about is allowing people to make mistakes [Member of Assessment Group]

There were also differences in expectations between healthcare professionals and advocates when the person WDLA was deemed to no longer have capacity to make their own decisions. Healthcare professionals believed advocates should adopt a 'best interest' approach once the person WDLA has demonstrated poor understanding of their situation, as they thought it was unethical to allow someone with diminished capacity to make decisions, as shown in the following excerpt:

How ethical is it to allow a demented person, who is with no insight, and no decision-making capacity, to make poor decisions? [Member of Assessment Group]

Under these circumstances healthcare professionals expected that advocates make decisions in the best interest of the person WDLA.

Conversely, advocates did not see the need for a 'best interest' approach as they considered themselves to be providing a client-directed service. Advocates only accepted

a referral if the person WDLA had the capacity to direct them; in circumstances where capacity was lacking, the advocate recommended referral to the Guardianship Board. Advocates judged the person WDLA to have capacity if they could indicate their wishes consistently; however it was not clear how much time was taken with the person WDLA to assess this capacity. Moreover, advocates believed their ‘proactive’ approach, which promotes early referrals, avoided the need for a ‘best interest’ approach, as early referrals gave advocates the time to establish a relationship with the person WDLA and gain an understanding of their preferences. Therefore, by the time decision-making capacity was lost, the advocate expected to have enough knowledge of the person WDLA to be able to represent their wishes in any decision-making process. In these circumstances advocates felt they were not taking a ‘best interest’ approach but were expressing the wishes of the person WDLA, which they would have established over time. Advocates were uneasy with the notion of providing non-directed advocacy:

...when you start talking about non-directed advocacy you’re talking about the advocate making a lot of judgements about things that we feel uncomfortable about, it means we are making those sorts of decisions. [Paula]

Healthcare professionals who shared similar expectations and perspectives on capacity of people WDLA to advocates were found to be more likely to have had a positive advocacy experience, while those with contrasting perspectives and expectations mainly had a negative advocacy experience. A negative experience led to greater reluctance to refer people WDLA to the advocacy service:

And I suppose from having that bad experience, those bad experiences, I’m now very reluctant to refer to an advocate, but I really – if there’s an absolute necessity, maybe once every two years, but it’s not where I would necessarily look to without a great deal of thought. [Member of Assessment Group]

These differences in expectations, underpinned by different disciplines and different priorities, had a negative impact on healthcare professionals' experience of the advocacy service and contributed to low referrals of people WDLA to the dementia advocacy service. Furthermore, the data suggested that the perception of the safety of people WDLA by healthcare professionals influenced people WDLAs' participation in the decision-making process.

Perceptions of capacity and risk influenced agency

Healthcare professionals believed undertaking capacity assessments to be an essential component of the advocate's role which required a '*sophisticated understanding of capacity*' [Medical professional interviewee]. Yet these professionals were of the view that the majority of advocates lacked this understanding, which was further contributing to relationship tensions. Conversely, advocates did not think capacity was an issue that they needed to address, given that they provide a client-directed service. Paula explained:

We're client directed so we're able to listen to people's wishes and to help them communicate those wishes. So as far as the capacity side of it, it doesn't really come into it. [Paula]

Advocates did not consider assessing a person WDLA's ability to direct them to be similar to assessing capacity. Although healthcare professionals expected advocates to have a deep understanding of capacity, it was unclear whether healthcare professionals had this knowledge themselves as they were unable to provide a clear description of how capacity should be assessed when asked by the interviewer during the focus groups.

Lack of clarity between healthcare professionals and advocates on establishing capacity resulted in differences of opinion on the capacity of people WDLA to live at home. These differences were more pronounced in circumstances where the person WDLA was in a hospital environment. Similar to the previous section, it appeared that healthcare

professionals shared a risk-avoidance approach while advocates shared a rights-based perspective which influenced their opinions on the capacity of people WDLA. Safety of people WDLA was paramount for healthcare professionals, while, in contrast, the key motivation for advocates was following the wishes of the person WDLA to remain living at home. Healthcare professionals felt that advocates did not consider safety and often pushed for people WDLA to return home without due consideration of the risks involved as shown in the example below:

...the advocate will come in, because the person that's demented will say, 'No. I want to stay home.' They're advocating for them not to go into a nursing home, to go back home, when they're a clear risk, and they've had probably numerous admissions before. So they're not understanding the risk factor. [Member of Assessment Group]

These professionals did not think there was a need for advocate involvement in a hospital context as they were of the view that there were more highly trained personnel in place in hospitals who understood risk and could make decisions in the best interest of the person WDLA. It was their belief that advocacy involvement only frustrated the process, as shown below:

I don't really see that that's their role to then be turning the process upside down, when you've already got professionals in there that have already looked at the situation, analysed it, and determined that it was in the person's best interests. And that used to happen a lot down at the hospital. [Member of Assessment Group]

This quote also demonstrates that the agency of the person WDLA in the decision-making process was not a consideration of this healthcare professional and contains the assumption that the healthcare professionals know best.

The majority of healthcare professionals attributed the differences in capacity assessments to an advocates' limited understanding of medical decisions and medical professionals'

duty of care for their patient. Others attributed it to a lack of training or a lack of critical pathways to follow when risk had been identified. An example is provided below:

I think in regard to their training, there were some people that didn't have a really good understanding of that. So the ideals just clashed because it was seen that the hospital was controlling a person against their [wishes] [Member of Community Care Group]

However, healthcare professionals acknowledged that advocates have often not been exposed to, or provided with, the same information as other professionals when making their assessment. In addition, advocates were often only brought in when a crisis had emerged and there was pressure to resolve the situation quickly meaning that there was limited time to process information, as shown in the following example:

And often that's probably a result of it being a really stressful situation the advocate gets involved in, because they land in the middle of this kind of volcano. [Member of Community Care Group]

Some healthcare professionals believed that these assessment differences between the parties could be minimised if advocates were '*involved right throughout the process and informed throughout the process, rather than just coming in sporadically*' [Member of Assessment Group]. However, the issue of patient confidentiality was raised as a potential obstacle. Healthcare professionals were concerned that it may be difficult to share patient information with the advocates without getting permission from the person WDLA and their own organisation.

In stark contrast, advocates believed healthcare professionals were risk-averse and frequently exaggerated the level of risk, resulting in negative outcomes for people WDLA. Support for the hypothesis of a risk-avoidance perspective on the part of healthcare professionals was provided by the views of one medical professional who

contended that reducing exposure to risk would enable people WDLA to remain living in the community for longer:

...don't let them go on trips, don't let them drive a car. All these things are setting themselves up for failure. I don't mean absolutely that all the time but this first stage of dementia is all about keeping people on the straight and narrow and if people are steady and not open to too much risk that's going to make them go down, then they'll stay at home longer. [Medical professional interviewee]

This is a further example of where prioritisation of safety by healthcare professionals had negated the agency of people WDLA and ignored the impact on their quality of life.

Advocates believed that an important aspect of their role was to encourage healthcare professionals not to give up on a person WDLA's wish to live at home but to try a little harder in supporting them. Some advocates considered that there had been numerous occasions where their involvement persuaded service providers to persevere with the person WDLA and continue to support them at home, as shown below:

...that's what the average role has been, to push the providers to go that little bit further, to stretch themselves a bit more, to not give up so easily, to see things a bit different. Because they're the ones that tend to be risk averse or whatever, it's all getting too hard. [Paula]

Nonetheless, there was a belief amongst healthcare professionals that it was easier for advocates to endorse risk, and to have a rights-based approach, as they were not responsible for finding and providing the necessary services to support people WDLA nor were they there to witness the situations where people WDLA ended up failing to cope at home and harming themselves. An example of their concerns is provided:

But they're not there to have to worry about this person falling into a heap, to try and get services to this person who – to see them falling over at home, perhaps because they're drunk, or whatever. They're not there to have to cope with all that, and to see the lack of dignity for that person. [Member of Assessment Group]

Unlike healthcare professionals, advocates were not constrained by organisational structures and services. Healthcare professionals found that a particular difficulty in dealing with people WDLA was that they often had limited family support, and some healthcare professionals agreed that they would be more open to risk and to facilitating agency in circumstances where the advocate was willing to act as an independent monitor. This would provide healthcare professionals with the assurance that there was someone regularly assessing the person WDLA's safety within the home, as shown in the following example:

...because to take a risk and say send someone home, if you had one support system saying 'yep we'll monitor, watch, we understand, we'll work with', to give a trial, that could be really useful. [Member of Community Care Group]

There was also an acknowledgement amongst healthcare professionals that they had become more risk-averse as society had become more litigious. Nevertheless, they were willing to accept a higher level of risk if the person WDLA had someone in their lives that could act as a substitute decision-maker and take on the responsibility for a decision:

...but if somebody with the capacity is saying 'look, it's risky for mum but that's what she really wanted', then that's fine, absolutely fine. So long as somebody with a brain is making the decision. [Medical professional interviewee]

Some healthcare professionals acknowledged there was a temptation to admit people WDLA to residential care facilities, which were perceived as safe environments, in order to reduce their risk of being exposed to litigation and of harm to the person WDLA, as shown in the following example:

So in regard to people covering themselves, and reducing risk, making sure the person's affairs are closed, has their medication, a residential care facility offers that, which the home situation may not. [Member of Community Care Group]

Although this practice provided protection for healthcare professionals it ignored the wishes of the person WDLA and their right to participate in the decision-making process. Differences in approaches to the assessment of capacity and risk were contributing to tensions between healthcare professionals and advocates. Perceptions of risk had an impact on the agency of people WDLA and their ability to participate in decision-making processes. Moreover, the results indicated that the risk-avoidance perspective of healthcare professionals and the rights-based approach of advocates influenced their opinions on whether people WDLA had the capacity to remain living at home.

Blurred boundaries risked agency

Some healthcare professionals expressed concern that advocates were not maintaining professional boundaries with people WDLA which led to their reluctance to refer people WDLA to the advocacy service. Healthcare professionals were of the opinion that some advocates became too close to their clients and therefore lost objectivity, which placed the person WDLA at risk of harm, as shown in the following excerpt:

I've actually been party to the advocates blurring the boundary, and becoming like a friend of the person, I suppose, and not having a balanced view. [Member of Assessment Group]

Healthcare professionals also expressed concern over the closeness of the relationship between people WDLA and advocates and the risk that the person WDLA could become too dependent on the advocate, and lose power of agency. This had the potential to counteract the dementia advocacy aspirations of empowering people to make their own decisions, thus restoring their agentic power. The following supports this concern:

And it actually can be quite detrimental to the client, because there becomes that interdependency, rather than trying to build some resilience in the client, and giving the client control of their lives. [Member of Assessment Group]

An additional risk to the agency of people WDLA was the amount of influence advocates possessed through this relationship. One advocate provided an example of the influence she exerted on a person WDLA to accept support services. In this situation acceptance of support may have prolonged the length of time the person WDLA was able to remain living at home:

So by getting my con- by him – me getting his confidence, he became confident enough to allow these things that I suggested to have happen. [Paula]

However, the dementia advocates argued that they were a client-directed service and that their role was only to express the views of the person WDLA and not to attempt to influence their decisions. Yet the data suggested there was variation between advocates in the interpretation of the term ‘influence’. Some advocates strongly believed that it was outside their remit to influence the person WDLA, even in situations of known abuse, as demonstrated in the following example:

...we are client directed and say somebody’s blatantly being financially abused but they choose to not do anything about it, yes, that is hard and gives you sleepless nights. [Paula]

Other advocates believed it was appropriate to exert influence in circumstances where they considered that the person WDLA was about to make an unwise decision. Paula provided an example where she had exerted influence on a person WDLA to change his will as she believed his choice of beneficiary was not sensible. Although she did not influence his new choice of beneficiary, and received no personal gain, she did play a role in influencing the person WDLA to change his will, as shown below:

And they both had loads of money and property, and I said to Paddy, ‘well, Paddy, that’s a bit dumb isn’t it, because you know Mick’s got more money than he could ever need, and you – have you thought about changing your will?’ and he said, ‘Yes, I have.’ I said, ‘because it really could get a bit complicated anyway,’ I said, ‘probably the government will end up with all the money.’ I

mean I didn't tell him what he needed to do with his will, and so he said, 'I'll think about it.' So he got this scrap of paper, and he was, he'd started thinking about it, and he was writing things down as he was thinking on it just on scraps of paper. I said, 'come on, I'll take you to a public trustee.' [Paula]

This advocate was of the view that influencing the person WDLA was justifiable if it resulted in positive outcomes and prolonged the length of time the person WDLA was able to remain at home. Here is a further example of the way in which this influence was exerted:

I said, I've told him about – I've seen people being taken. 'Oh, they couldn't do that to me,' he said. I just said, 'so you think you're special? And you think they wouldn't do it to you?' I said, 'that's rubbish. They would, they will do it to you, they can come.' I said, 'I've seen it. I've seen people taken away out of their homes. And it can happen to anybody, if they just – they have the power to do that. [Paula]

These examples showed that unless there were checks and balances in place there was a risk that an advocate's influence may be exploited or underutilised, either of which could result in negative outcomes and a loss of power of agency for people WDLA. There was also a risk that the views of the advocates might be prioritised over the wishes of the person WDLA.

A further issue which emerged from the data was the length of time advocacy support was provided to each person WDLA. Several healthcare professionals found that it was difficult to project an end to advocate involvement as shown below:

Like the person I'm thinking of before, it seemed to go on for so long, the involvement, it was all good involvement, but I couldn't see an end to it, because it was just going to going on, and on, and on. [Member of Assessment Group]

Consistent with this, advocates described their relationship with people WDLA as a 'lifelong relationship' [Paula] and were content to remain involved in the lives of their

clients for as long as the person WDLA desired. Advocates acknowledged that they had not given the ending of this relationship much consideration. This may be remiss given that many of their clients had limited social contact other than the advocate. Advocates were also reluctant to end their interaction completely as there was concern that as dementia progressed the person WDLA may be unaware when they required support. By remaining present advocates believed they could act as a prompt and reduce the potential for harm, as shown below:

So if we don't keep that connection we'll know that after a while we'll stop hearing from them. They'll stop calling us. Not because they don't need the support of an advocate, but because they need somebody proactive to say 'how are you going, are you okay.' [Paula]

If the numbers of clients greatly increase, it may be difficult for advocates to maintain the same amount of time and frequency of interaction for each person WDLA and further thought may be needed about how this reduction might affect the emotional well-being of the client.

Some healthcare professionals were of the view that there were also risks for advocates in their relationships with people WDLA. There was a risk, due to the loss of insight, that advocates could be accused of financial impropriety when assisting with the financial affairs of people WDLA, as shown below:

If they are doing that when it's reasonably clear that person is not able to manage their financial service, they actually expose themselves to the risk of being accused of interfering with that, or worse still. And that's the reality. [Medical professional interviewee]

The data suggested that unclear boundaries of this relationship regarding the level of influence, withdrawal processes, and assistance with finances were placing the person WDLA and the advocate at risk while also leading to reluctance by healthcare

professionals to refer people to the advocacy service. These blurred boundaries were shown to be a risk to the agency of people WDLA and to have the potential to prioritise the views of advocates over the wishes of the person WDLA.

Structural and interactional challenges limited opportunity

The data identified four social structural and interactional challenges which limited the use of advocacy services and had an impact on the effectiveness of the advocacy service in facilitating agency. These were: structural constraints; inconsistency between advocates; communication style of advocates, and; the service being promoted as dementia advocacy. Each of these constraints and their impact for people WDLA is discussed further below.

Structural constraints

Structural constraints within advocacy and healthcare organisations were identified as a major barrier to use of the advocacy service. Some healthcare professionals considered their organisations to be already struggling to cope with the number of people WDLA and the involvement of an advocate was only seen as placing extra demands on them without providing significant benefits for people WDLA. This led to reluctance to refer people WDLA as it was not just the initial referral that was considered time intensive, but also the on-going interactions with the advocate once they became involved. An example from the Community Care Group is provided:

I have at times not referred to the advocacy service because it's been a lot of work and it doesn't seem to have a lot of benefit to me or the client. [Member of Community Care Group]

Reluctance to involve advocates was particularly evident among healthcare professionals working in the acute care sector. These professionals believed that they were under considerable pressure to discharge a patient as quickly as possible, and the involvement of

advocates was seen only as prolonging the process and adding to the complexity of the situation:

It's such a big push to process, to accept the referrals, process and discharge, that often or not, as we have noted, that advocacy takes time, it's not something that happens quickly overnight, and so this is not used, so the referral is not made. Because of that strong push at the moment just to process and accept and tend to the immediate needs and discharge. [Member of Community Care Group]

Healthcare professionals' perceived pressure to enforce the requirements of their organisation and discharge patients WDLA quickly and these social structures were limiting advocate involvement.

There was also a perception among healthcare professionals that the advocacy service was under-resourced, which further contributed to their reluctance to involve advocates to support people WDLA. One member of the Assessment Group had past experience of trying to refer a person WDLA to the advocacy service which was rejected due to limited resources. This experience had left the healthcare professional reluctant to refer any further people WDLA to the service. Some healthcare professionals, who perceived advocacy positively, were of the view that there were not enough dementia advocates to meet the current demand, as shown in the following example:

I'd go so far as to say that there's not enough advocacy services available for people with dementia. The situation we've got at the moment, there's one particular person who is very active, and I'd like to see another ten of her, because I think there's the need. [Member of Assessment Group]

Advocates acknowledged that it was sometimes difficult to apportion their time as they were not solely working with people WDLA using this 'proactive' approach but were also providing 'issue-based' advocacy to older persons living in the community and residential care facilities. Advocates accepted that if faced with numerous 'issue-based' cases there

was the temptation to prioritise these over ongoing support to people WDLA, as it was quicker to gain resolution of issues. Furthermore, there was reluctance by advocates to promote the service to the wider community as they feared they did not have the resources to meet the demand:

...because there aren't a lot of us, we can't really go out and promote and advertise too much because we might get flooded with people and we wouldn't be able to meet the demand. [Paula]

These results appear to indicate that the social structures in which healthcare professionals operate, and the organisational structure of the advocacy service, limit people WDLAs' understanding of advocacy and opportunity to access advocate support.

Inconsistency between advocates

Healthcare professionals found wide variations in the skill set of advocates and believed there to be a direct correlation between the advocate's level of expertise and their level of interaction with them. The more skilled the advocate was perceived to be the more willing healthcare professionals were to engage with them, as shown below:

At different times I have had dealings with different folks from advocacy. Their personalities and their knowledge have varied quite a bit. To be quite blunt, some of them I found to be complete pains in the arse who had very little understanding of what was going on. Others have been just amazing. [Medical professional interviewee]

In order for advocates to be effective, healthcare professionals contended that it was essential for advocates to be well trained and have an in-depth understanding of dementia and its complexities. Similar to previous findings, reference was made to the importance of understanding capacity as shown in the following quote:

But they must have training about, they must understand about dementia, they must understand about that, they must understand why we do what we do. If they don't understand that, they don't work well. That's it. No point someone coming and negotiating with you, who has no understanding of dementia and

tries to pretend this person, or assume this person has full capacity. It doesn't work. [Member of Community Care Group]

Data also indicated that there were more positive interactions between healthcare professionals and advocates in circumstances where the advocate was specifically dedicated to working with people with dementia rather than providing advocacy across a wide range of areas. This improvement was attributed to the advocate's increased level of understanding of dementia:

...when there's been a specific person working for people with dementia, it's definitely improved the relationship. [Member of Community Care Group]

Although most advocates had worked in the area of aged care prior to joining the organisation, almost all of them had no prior advocacy experience. In spite of this, the organisation had provided no specific training to the advocates. As Paula described:

I didn't receive any training, I arrived at my office and had a bit of a handover by my predecessor and left to it, so it was a steep learning curve for the first week. [Paula]

Furthermore, the 'proactive' approach used by advocates working with people WDLA was relatively new and there were few procedures in place within the organisation to assist these advocates in conducting their role. In fact one advocate acknowledged that:

We have always felt pretty much like we've sort of been making it up as we go along. [Paula]

These results indicate that advocates' lack of training on advocacy and dementia and the variation in the skill level of advocates as assessed by healthcare professionals is negatively affecting perceptions of the advocacy service.

Lack of training and organisational procedures also appeared to contribute to inconsistent approaches amongst advocates in relation to: the way in which introductions to people

WDLA were conducted; the type of service provided; and the documentation maintained for each client. For example, some advocates thought it was important from the outset to explain their role to the person WDLA while others focused on building a relationship first. Another was concerned that mentioning advocacy could alienate people WDLA, and, for this advocate, building a connection with the person WDLA was prioritised over explanation of the advocacy service, as shown below:

So, it's – to me, it's about – I'm just – I'm this person, ok, who's – and we have a chat and a joke and you tell me about your life and I tell you. [Paula]

A further example of the variation among advocates was in relation to the type of service provided. Most advocates were adamant that the type of service provided by them was not a befriending one, while one advocate thought it was not so clearly defined. This advocate was of the view that establishing a trusting relationship was critical to understanding the person WDLA's needs and wishes and that this relationship could be perceived as befriending, as demonstrated in the example below:

I mean it's a fine line obviously because there needs to be that the person needs to want the advocate to be working with them and I mean you're going to make an effort to get on well with the person. So I guess in a way it's a befriending role. [Paula]

Some participants WDLA also viewed the relationship with the advocate as a friendship; both Mary and Ann referred to the advocate as a '*friend*' during their interviews. This was plausible given that the majority of participants WDLA in this study had limited social contact apart from the advocate, which may have influenced their perspective. However, the actions of some advocates could have also contributed to this view, as, for example, one advocate introduced Ann to her family, as Ann recalled below:

Paula took me home, introduced me to her mother and father, to her husband and children, as if I was a friend of the family. Now, that stands out as being ridgy-didge. [Ann, age>80]

In contrast, one of the other advocates was less concerned with building the relationship with the person WDLA and therefore maintained a professional distance. It was important to this advocate to ensure they were not viewed as a befriending service:

I'm not sitting around having cups of tea and what have you. In saying that, there are other advocates who do it a little bit differently and probably do get a little more friendly, but I can see that's just fraught with disaster both for the advocate and for the client. [Paula]

There were also significant differences between advocates on how interactions and proposed actions for their clients were documented. One advocate had chosen to document all agreed actions in a folder that remained with the client. This enabled the person WDLA to review the agreed actions at any given time. As the advocate explained:

I just wanted to package up my role for the person, because it seemed wishy-washy to me, so I thought, well how's it feeling for the person. [Paula]

In contrast, two other advocates were of the view that a good thing about their organisation was the lack of paperwork, and these advocates were opposed to using a formalised and documented system when interacting with people WDLA, as shown in the following example:

I just think it gets more confusing when I prefer to be informal and I associate folders and papers with formal. [Paula]

There was some consistency in documentation practices between advocates, as the same electronic database was used to document interactions with clients, yet large variation in the level of detail was identified. Some advocates inputted long, detailed entries, while

others provided bullet points, and although advocates had tried to standardise their systems, consensus had yet not been reached:

...we come to the conclusion that whatever system we want probably isn't going to work very well anyway, let's just keep doing what we're currently doing.
[Paula]

Lack of guidelines, standards and training from the advocacy organisation caused inconsistencies between advocates resulting in healthcare professionals becoming concerned about the professionalism of the service and in reluctance to refer people WDLA.

Communication style

The communication style of some advocates was found to generate negative perceptions of the advocacy service and acted to deter healthcare professionals from referring people WDLA. The term 'respect' emerged as a key element of healthcare professionals' approach to communicating with advocates. It was not essential that advocates agree with the opinions of healthcare professionals, but it was expected that mutual respect was shown in their interactions. Healthcare professionals believed that this was lacking in the communication style of some advocates, as shown in the excerpt below:

In fact one of the people I respect most of all will be very prepared to tell me what she thinks, and that's fantastic. I respect that. I respect that view. But you know, it's a working relationship. There have been people where you just think, oh my God. [Medical professional interviewee]

The style of communication and language used by advocates appeared to be influenced by their perspective of their role. Evidence of this was provided by Paula when she described her role as a 'bit of a watchdog, growling in my kennel'. This particular advocate perceived her role as a protector of people WDLA from potential abusers and was of the view that almost all people WDLA were at high risk of abuse. An example of the emotive

language used by this advocate when describing her role is provided in the following excerpt:

I'm a presence in their life, almost like a guard dog, because there are people on the periphery waiting to take advantage, but when they know you're there they tend to back off. [Paula]

Arising from their understanding of the legislative framework, one advocate considered that she played an important role in ensuring people WDLA received adequate services. However, this same advocate also interpreted her role as one of policing of the services provided to people WDLA. An example of similarly combative language about her interactions with service providers is shown below:

I can go and it says in the Aged Care Act you're meant to be doing that. You're not and if you don't fix it, I will go to the complaints unit and they'll go through you like a dose of salts. [Paula]

This kind of language was not conducive to building a rapport with healthcare professionals, particularly when she described the environment she had to enter on behalf of the person WDLA as like 'going into a battle'. Consistent with this approach healthcare professionals' found many advocates extremely difficult to communicate with and there was a prevailing belief that advocates failed to recognise that healthcare professionals were also interested in attaining the best possible outcome for people WDLA, as exemplified below:

...the advocate could, well, scoff and be quite rude to the service providers who are themselves doing their very best to help that person too. So to be treated as an enemy which we do sometimes does not feel good. [Member of Home and Social Support Group]

Poor communication style resulted in healthcare professionals' reluctance to involve advocates. However, not all advocates appeared to demonstrate this confrontational communication style. One of the other advocates believed it was essential that health

professionals and advocates work together to facilitate the agency of the person WDLA. This advocate felt that the current ‘proactive’ approach used in dementia advocacy was less combative than the ‘issue-based’ model used for all other clients and was therefore more conducive to improving the relationship between healthcare professionals and advocates. Paula explained:

It’s much more collaborative, so I encourage a team approach. I build, it’s like building that team around people, gradually, and if it’s what they want, and if it’s what they need, then – and so I have very, very different relationships with service providers now. [Paula]

Although good communication and rapport with healthcare professionals were felt to be important, advocates recognised that this relationship must not lead to a loss of objectivity. Advocates feared that if they became too close to healthcare professionals it might be difficult for them to raise the concerns of people WDLA with them, and therefore a balance had to be found. Paula explained that:

If they get too cosy, too friendly, it makes it hard for them to be an effective advocate where they’ve got to have the hard conversations. So finding the right sort of level to pitch things at too is pretty tricky. [Paula]

The cultural context of each advocate appeared to influence their communication style and their relationship with healthcare professionals. Poor communication style seemed to negatively affect the number of referrals to the advocacy service. It was suggested by a member of the Community Care Group that further education should be provided to healthcare professionals on the benefits of advocacy involvement and that this could help to improve communication between the parties and help to overcome the current perceptions of advocacy as adversarial. Nevertheless, there was concern from advocates that over-familiar relationships with healthcare professionals might compromise the wishes of the person WDLA, and the importance of balance was highlighted.

Service promoted as dementia advocacy

The stigma associated with dementia led to reluctance to provide patients with a diagnosis as evidenced from the example below:

I don't know that I use the word dementia first off. I think most people are really very aware of what's going on and sometimes you need to clarify what's happening. ...it destroys people's lives if you say you've got Alzheimer's. [Medical Professional Interviewee]

As a result of this stigma, healthcare professionals were of the view that the vast majority of people WDLA were uncomfortable with the term 'dementia' and did not like to acknowledge their condition. The advocacy organisation brochure used the term 'dementia' throughout, and healthcare professionals and advocates alike believed that these brochures acted as a deterrent. Paula explained that:

It's got 'dementia' plastered all over it which I think is an issue if service providers are just putting these to clients and not really explaining, even though I've explained to them what we do. It's the word dementia. People don't want to associate with it. [Paula]

Members of the Assessment Group have a legislative duty under the national Common Community Standards to notify clients of a right to an advocate, but these professionals acknowledged that they were often reluctant to provide people WDLA with brochures unless the person had openly accepted a dementia diagnosis or had someone else with them who could receive the brochure. An example from this group is provided:

So I don't always do it, but if there's somebody there who knows full well the client's got dementia, and is obviously equipped to speak on their behalf, then I give it to them as well, so they've got a bit of extra information. [Member of Assessment Group]

Although there was reluctance to advise people WDLA of the dementia advocacy service, members of the Assessment Group acknowledged that they were more inclined to

promote dementia advocacy services if abuse of the person WDLA was suspected, as shown below:

I'd probably push it a bit harder if I'm getting a sense that there's some sort of underlying issue that you can't just quite the nub of it, and the person seems more vulnerable than usual, but that's often a bit of a gut instinct thing, as well as identifying clear conflicts between family members. [Member of Assessment Group]

These data suggested that the term 'dementia' used in the advocacy brochure was a factor in healthcare professionals' reluctance to advise people WDLA about the advocacy support services available to them.

Conclusion

The data presented in this chapter revealed numerous benefits of advocate involvement and a general support for the advocacy service. Advocate involvement protected the right of people WDLA to participate in healthcare decision-making processes by facilitating their power of agency through enhanced communication and the restoration of their agentic power. The relationship between the person WDLA and the advocate also promoted the power of agency of people WDLA by reducing anxiety and increasing self-belief. Additionally, tangible supports provided by advocates assisted in enabling people WDLA to remain at home. These data suggest independence, time, style of communication, supportive decision-making, cultural context of the advocacy organisation and the relationship between the person WDLA and the advocate were important features of advocacy that facilitate participation of people WDLA in the decision-making process.

This chapter also demonstrated that there were significant challenges for the advocacy organisation which are having an impact on the effectiveness of the service. There was a marked lack of understanding of advocacy by healthcare professionals and people

WDLA. There were also significant differences in the perceptions of capacity and risk of people WDLA among healthcare professionals and advocates and these perceptions influenced the expectations of advocates, the perceptions of the advocacy service, the agency of people WDLA and their right to participate in the decision-making process. These differences were influenced by the prioritisation of safety and the risk-avoidance approach taken by healthcare professionals versus the rights-based approach adopted by advocates. Blurred boundaries of advocates and the advocacy organisation were identified to be a risk to the agency of people WDLA, while structural and interactional challenges limited the opportunity of people WDLA to avail themselves of advocacy support. All of these factors contributed to tensions in the relationship between healthcare professionals and advocates that negatively affected the referral rate of people WDLA to advocacy services. These features of advocacy and the mechanisms which facilitated and constrained the agency of people WDLA are discussed further in the following chapter.

Chapter 6: Discussion

'The capacity to exercise control over the nature and quality of one's life is the essence of humanness' (Bandura 2001)

Introduction

The overarching aim of this study is to explore the power of people WDLA to participate in decision-making processes with advocacy support. This was achieved by examining the impact of dementia on agency, the factors influencing agentic action and the features of advocacy that facilitated participation of people WDLA. This chapter discusses the findings from the previous two chapters, theorising on the generative mechanisms underpinning events. To explore agency it was necessary to examine the power of agency and agentic power of people WDLA, as their participation not only relied upon their ability to take action but it also depended upon their ability to act independently of the constraining power of social structures (Campbell 2009). As a critical realist study, the analysis of agency entailed understanding the generative mechanisms that instigate events, such as the structures, powers and relations which may or may not be directly observable, but are real and can be identified through their effects (Dobson, Jackson & Gengatharen 2011; McEvoy & Richards 2003). Danermark et al.'s (2002) method of 'abduction' and 'retroduction' was used to identify these generative mechanisms responsible for constraining and enabling agency of participants WDLA. This method helped to ensure consistency in the analysis of data across the different data sources and data collection methods.

Using a critical realist framework, this study has identified four critical components of agency: power of agency; agentic power; self-belief, and; present and future orientations of agency. These four components, when activated, have the power to facilitate participation of people WDLA in the decision-making process. Agentic power of people WDLA was found to be constrained by healthcare professionals' power to influence assessments of decisional capacity and the risk-averse society in which these professionals operate. Three features of advocacy were identified which had the power to significantly enhance the four critical components of agency which were: time spent with the person WDLA; positive cultural context of advocates, and; a trusting relationship between the person WDLA and the advocate. The discussion is presented in four main sections which address the impact of dementia on power of agency, the factors influencing agentic action, the features of advocacy that facilitated participation of people WDLA and their power to participate in the decision-making process, reflecting the research questions and its overall aim.

Impact of dementia on power of agency

Data from Chapter Four showed that the power of agency of participants WDLA was constrained by loss of functional capacity. As individuals lost functional capacity their choices and their control over their own lives were restricted. This was seen through the loss of ability to drive, to work and to manage financial responsibilities. Many authors have reported that the inability to drive was a major concern for people with dementia as it is associated with a dependency on others (De Witt, Ploeg & Black 2009; Frazer, Oyebode & Cleary 2012; Harris 2006; Sait 2013). This loss may have particular significance in Australian culture as only 16 per cent of Australians were found to use public transport (Australian Bureau of Statistics 2013). In addition, public transport is not always easily accessible in Australia; a 2010 report showed that nearly half (48%) of adults without

access to a personal vehicle felt they sometimes or often had difficulty getting to places or events (Australian Bureau of Statistics 2013). Further to increased reliance on others, this study showed that loss of the ability to drive diminished power of agency, as choices to go shopping, visit friends or participate in hobbies became limited, and it was this loss which was extremely distressing for participants WDLA. Loss of power of agency reduced the person WDLA's ability to participate in self-affirming or meaningful activities, resulting in decreased self-esteem and loss of identity. Others have reported how identity is frequently affirmed through participation in these type of activities (Caddell & Clare 2011; Parsons-Suhl et al. 2008; Steeman et al. 2006). Diminished power of agency and inability to participate in activities narrowed the social world of participants WDLA, thus increasing their risk of social isolation. This finding is supported by the results of a review (Nicholson 2012) that found social isolation negatively affected a person's well-being and could even result in detrimental health outcomes. In summary, loss of functional capacity reduced power of agency, limited the ability to participate in self-affirming and meaningful activities and narrowed the social world of participants WDLA.

Although participants WDLA were losing power of agency, this study showed that at the same time the majority of them were exerting power of agency to employ strategies to cope with the impact of dementia. This finding is consistent with several other studies which found that the majority of people with dementia did not undergo it passively but instead faced constant tension between accepting dementia and fighting it (De Boer et al. 2007; Preston, Marshall & Bucks 2007; Steeman et al. 2006; Steeman et al. 2007).

Macquarrie (2005) referred to this as the dialectical tension between agency and objectification. Although the majority of people WDLA can adjust to the impact of dementia, some are unable to adapt and become depressed (Duane, Brasher & Koch 2013; Steeman et al. 2006) yet little information was provided in the literature to explain this

phenomenon. Data from this study suggest that the temporal orientations of agency and self-belief play a role in a person's ability to adapt to dementia as these factors have an impact on the power of agency of participants WDLA.

Temporal orientations of agency

People WDLA exert different elements of agency in response to the challenges posed, and exploring these temporal orientations can facilitate an understanding of the actions and behaviours of people WDLA in response to these challenges. As previously discussed in Chapter One, there are three different constitutive elements of agency, iteration, projectivity, and practical evaluation, and these elements are orientated toward the past, future and present respectively (Emirbayer & Mische 1998). Consistent with previous studies (Duane, Brasher & Koch 2013; Frazer, Oyebode & Cleary 2012; Harris 2006; Sait 2013), this study found that retaining power of agency and autonomy was very important to all participants WDLA and that in efforts at maintaining control their actions were predominantly orientated to the past and present, with little focus given to the future. These three orientations of agency expressed by participants WDLA are discussed further below.

Past orientation of agency

This study established that retaining agency and autonomy was a central aim for participants WDLA and that in their efforts to maintain agency, the actions of some of the participants WDLA tended to be more orientated towards the past. Emirbayer and Mische (1998) found that during periods of significant loss, a shift in orientation to the past, through habit and repetition, can become a stabilising influence. Consistently in this study, the home provided an important stabilising influence, as even though power of agency was diminishing, by remaining at home participants WDLA were still able to exert a level of agency over their lives. A move away from the home was perceived negatively as it was associated with relinquishing power of agency. The routines and

familiarity of the home also helped some participants WDLA cope with memory loss and maintain independence and these participants feared they would not cope in a new environment. Some authors viewed the home as a place that people WDLA retreated to for safety (Frazer, Oyebode & Cleary 2012; Harris 2006), while others viewed it as a place which provided protection from judgements of others (Askham et al. 2007; Van der Roest et al. 2007; Wilson 2001). This study indicated that the home was also an environment which protected and helped maintain power of agency and autonomy over the daily lives of participants WDLA.

Although, an orientation to the past can provide stability, people expressing this orientation may also resist change in an effort to hold off uncertainty and protect against further loss (Emirbayer & Mische 1998). This study found that some participants WDLA were resistant to change and feared that interactions with others may further diminish their power of agency and decision-making control. Although an orientation to the past assisted participants in their struggle against loss of agency, it was also shown to cultivate an environment of mistrust for some participants WDLA, leading to reluctance to engage with support services. Therefore, a negative aspect of a past orientation of agency is that it can further contribute to a narrowing of the social world of people WDLA and increase their reluctance to engage the support of others.

The study has also shown that there were benefits and disadvantages in recalling past experiences and achievements for participants WDLA. For some it helped to maintain identity and provide greater confidence in current capabilities, while for others it served only to emphasise loss and diminished self-belief. This finding is consistent with a review of the experiences of people with dementia (Steeman et al. 2006) which reported that recalling past experiences can cause feelings of competency while at the same time, under different circumstances, can create feelings of incompetency. Therefore, recollection of

past experiences and a past orientation has the potential to either increase or inhibit the self-belief of people WDLA.

Present orientation of agency

The majority of participants WDLA had the ability to temporarily shift their orientation to the present in order to adapt to and cope with the impact of dementia. The main strategies identified were behaviour modification strategies, tangible actions, peer support and practical adaptations around the home. This present orientation enabled individuals to make judgements on the best course of action to take when presented with options (Emirbayer & Mische 1998). The actions taken were influenced by the person's personality, life history and current situation (Woods 2001). Although numerous strategies were identified, they appeared to be aimed either at helping the participant WDLA cope with loss or at finding ways to maintain power of agency. This is consistent with the constant tension described earlier between accepting and fighting dementia (De Boer et al. 2007; Preston, Marshall & Bucks 2007; Steeman et al. 2006; Steeman et al. 2007).

Behaviour modification strategies, such as minimisation of the condition and appreciation of existing capabilities, have previously been reported in the literature (De Boer et al. 2007; Macquarrie 2005; Steeman et al. 2007). This study also identified peer support as an important coping strategy for some participants WDLA. Peer support not only offered company, support and entertainment but it also provided participants WDLA with a community where they felt accepted as their current selves. The tangible actions and practical adaptations taken by participants WDLA were aimed at maintaining autonomy and reducing the risk of harm so that they could continue to live at home in a place perceived as enabling power of agency. Steeman et al. (2007) contended that strategies employed by people WDLA were aimed at protecting identity. This study would suggest

that the strategies employed by participants WDLA were aimed at protecting identity, autonomy *and* power of agency.

The power of participants WDLA to implement coping strategies was influenced by their ability to shift their temporal orientation to the present. The ability to shift to the present relied upon a person's belief in their power of agency, as evidenced in interviews with two male participants (John and Adam). John was overcome by grief and believed there was nothing he could do to improve his situation, while Adam was focused only on his lost capabilities, which induced feelings of hopelessness and powerlessness. These feelings significantly affected power of agency, as Bandura stated:

Unless people believe they can produce desired results and forestall detrimental ones by their actions, they have little incentive to act or to persevere in the face of difficulties. (Bandura 2001, p. 10)

Consequently, the ability to orientate to the present relies upon a person's belief in their power of agency, which is important to the well-being of the person WDLA, as it is this orientation which enables judgements to be made on the best course of action to take.

This study indicates that a temporal orientation to the present can help participants WDLA cope with the impact of dementia and enhance their power of agency.

Future orientation of agency

This study has shown that the majority of participants WDLA were reluctant to orientate their actions to the future and preferred to deal with each challenge as it arose. This reluctance is consistent with the findings of other studies (Caddell & Clare 2011; De Boer et al. 2007; Steeman et al. 2006; Steeman et al. 2007). Emirbayer & Mische (1998) explained that while immersed in a temporal orientation towards the future, an individual constructed varying images of where they thought they were going, where they wanted to go and how they can get there. However, in this study the majority of participants WDLA

did not want to construct images of their future, as it was associated with a total loss of agency due to the progressive nature of dementia. Consistent with other studies, the future for some people WDLA was feared more than death (De Witt, Ploeg & Black 2009, 2010). Therefore, in order to cope with dementia and remain positive, participants WDLA avoided orientating their actions to the future.

Younger participants WDLA, and those who had witnessed other family members with dementia, expressed more fear over their future. Reports of 'fear of the unknown' and 'fear of being a burden' were consistent with findings from other studies (Cahill et al. 2004; De Boer et al. 2007; Steeman et al. 2007). An additional fear emerging from this study was 'fear of future decision-makers' as there was concern that future decisions taken on behalf of the person WDLA would not be representative of their views. For many of those interviewed, family support was limited, thus restricting the choice of future substitute decision-maker. Lack of an appropriate substitute decision-maker can therefore increase anxiety for people WDLA which can lead to greater reluctance to orientate towards the future. Although avoidance of orientating to the future may be a coping mechanism, it diminished the opportunity for future planning while participants WDLA still had the capacity to do so. Future planning may have the potential to alleviate some of the fears of participants WDLA identified in this study, as it could afford them a level of control over their future. It also has the potential to empower people WDLA, as demonstrated by Jane through the organisation of her own funeral. The challenge is providing the right context so that people WDLA feel less anxious about orientating to the future and can perceive the benefit of future planning while they still have capacity to undertake such planning.

In summary, this study has shown that temporal orientations of agency are generative mechanisms which influence the actions of participants WDLA. A past orientation of

agency was a mechanism which could enhance or constrain the power of agency of participants WDLA. While temporal orientations to the present and future were mechanisms which could facilitate and enhance the power of agency of people WDLA. Although participants WDLA seemed reluctant to shift orientation towards the future because of the fear associated with their future trajectory. This study has also identified self-belief as an important mechanism in shifting orientation of agency to the present. This mechanism is further discussed below.

Self-belief and self-stigma

The way in which a person WDLA views their cultural context influences their understanding of their world and of their capabilities within it (Danermark et al. 2002). Consequently, the way in which a person perceives their dementia diagnosis will affect their behaviour and influence their power of agency. From the outset of this study, the term ‘dementia’ was found to be unacceptable for the majority of study participants WDLA, and words like ‘embarrassed’ and ‘disappointed’ were frequently used in reference to their symptoms. Healthcare professionals appeared to acknowledge this stigma, as they were also reluctant to use the term ‘dementia’ in their interactions with participants WDLA and often avoided providing them with information on the condition. Stigmatisation of dementia has been reported to lead to low self-belief and low self-esteem for people with dementia (Batsch & Mittelman 2012; Katsuno 2005; Link & Phelan 2006; Van der Roest et al. 2007). This is significant as Gecas (2003) reported that people with high self-belief tended to think of themselves positively, while those with low-self-belief were more likely to perceive themselves as powerless and helpless. Therefore, how participants WDLA viewed dementia and their attitudes towards it affected how they felt about themselves and this had an impact on their ability to take action.

Throughout life a person constantly assesses and reassesses themselves through the evaluation of others or, more accurately, through their perception of this evaluation (Danermark et al. 2002; Gecas & Schwalbe 1983). This study showed that participants WDLA were cognisant of the views of others and it was important for them not to be defined solely by their cognitive impairment. This was consistent with other studies which reported that being valued was more significant than the loss of cognitive ability for people with dementia (Lyman 1998; Steeman et al. 2007; Van der Roest et al. 2007). A further study has shown that often people with dementia felt 'substandard' in comparison to others or their past selves (Preston, Marshall & Bucks 2007). This study showed that for some participants WDLA the concern over the evaluation of others was so acute that it led to them actively withdrawing from others for fear of being negatively judged. These findings were consistent with other studies, where the stigma of dementia was reported to increase the social isolation of people with dementia (Batsch & Mittelman 2012; De Witt, Ploeg & Black 2010; Link & Phelan 2006; Scholl & Sabat 2008; Snyder 2001). Self-stigma associated with dementia therefore has the potential to diminish self-belief and to lead to withdrawal from interactions with others. This withdrawal diminishes the opportunity of people WDLA to be involved socially or to participate in decisions at a service delivery or policy level. Consequently, the cultural context of participants WDLA appears to be an important factor that influences their self-belief, which in turn affects their power of agency.

Factors influencing agentic action of people WDLA

Critical realism recognises that agency and social structures are separate entities with their own properties and powers but, in spite of this, that each has an effect on the other (Angus et al. 2006; Bhaskar 1975). Through a process of 'abduction' and 'retroduction', a theory emerged on the causal interplay between agency and the cultural and structural

conditions that inhibit and enhance participation of people WDLA in the decision-making process (Danermark et al. 2002). Through this process, the study identified two mechanisms responsible for constraining the agentic power of participants WDLA, these were: the power of healthcare professionals and carers to influence decision-making capacity assessments, and; a risk-averse society. In contrast, a trusting relationship between a proxy and the person WDLA was found to be a mechanism which could enhance or constrain the power of agency of participants WDLA. These three generative mechanisms are discussed further below.

Power to influence decision-making capacity assessments

Participation in the decision-making process was extremely important to participants WDLA yet the majority of participants perceived that they were being marginalised in the decision-making process, often by well-meaning family and friends. From their experiences, it appeared that these informal carers were equating a dementia diagnosis with an immediate loss of decision-making capacity. This perspective led to decisions being taken on behalf of the person WDLA without any consultation with them. Some healthcare professionals also shared this perspective and believed that people WDLA should not be allowed to make decisions or to participate in the decision-making process. These cultural contexts, constraining participation, were also reported in another study in which the majority of participants with dementia felt they were not adequately listened to by both professionals and family carers (Tyrrell, Genin & Myslinksi 2006). Brannelly (2006) similarly found that healthcare professionals often approached people with dementia with '*social disregard*' (p. 8), ignoring their decision-making capacity. These perspectives failed to recognise that although dementia inevitably leads to loss of decision-making capacity, the loss is gradual and at any given time a person with dementia might have the capacity to make certain decisions, while at the same time being unable to make others (Whitlatch & Menne 2009). This study showed that equating

dementia with a lack of decision-making capacity removed agentic power from participants WDLA. These cultural contexts had the power to marginalise participants WDLA in the decision-making process.

Participants WDLA appeared to respond to this exclusion in one of two ways: they either chose to accept it or they confronted it. Acceptance generated feelings of frustration and powerlessness while confronting it resulted in reluctance or withdrawal from engagement with others. Both responses negatively affected the well-being of participants WDLA. Research has shown that people with dementia involved in daily decisions have a better quality of life, lower levels of depression and increased levels of self-esteem (Manthorpe & Moriarty 2010; Menne et al. 2008; Van der Roest et al. 2009; Whitlatch & Menne 2009). Despite these benefits, participants WDLA were being excluded from participation in the decision-making process due to a lack of understanding of the variability of the impact of dementia on decision-making capacity by both healthcare professionals and informal carers.

This study also showed that assessments of capacity were strongly influenced by an assessor's cultural context. These cultural contexts differed between and among healthcare professionals and advocates, leading to differences in capacity assessments for people WDLA. Consistent with other research (Clarke, C 2000; Sait 2013), this study found that for the majority of healthcare professionals a culture of safety predominated, which led to a prioritisation of safety over agency. This prioritisation constrained agentic power of people WDLA and reduced their ability to participate in the decision-making process. In contrast, advocates promoted a rights-based culture, resulting in a prioritisation of agency over safety, but this approach had the potential to lead to an over-estimation of capacity that could jeopardise the safety of participants WDLA. These differences in cultural contexts and in the subjective nature of capacity assessments

contributed to divergent opinions on capacity and negatively affected perceptions of advocacy. Difficulties in determining decision-making capacity and differences in capacity assessments were also reported in other studies, even amongst clinicians assessing the same patient (Lowe et al. 2000; Samsi & Manthorpe 2013). Contributing to this difficulty is the lack of a specifically designed technique to determine decision-making capacity (Lai & Karlawish 2007). Moreover, the lack of a shared understanding of decision-making capacity and a discordant approach to capacity assessments is increasing the risk of marginalisation of people WDLA in the decision-making process.

As previously discussed, the United Kingdom, under the *Mental Capacity Act 2005*, which operates in England and Wales, was the first country to provide guidance and pass legislation on decision-making capacity. Two major underlying principles of this legislation are targeted at protecting the agentic power of people with dementia; the legislation states that a person must be assumed to have capacity unless it is shown that they lack capacity, and further that capacity must be assessed as each decision arises (Mental Capacity Act 2005). Therefore, a person with dementia can no longer be judged incapable of making decisions simply because of their diagnosis; while, at the same time, this legislation also recognises that capacity can vary. In the United Kingdom this Act, if enforced, has the potential to restore agentic power to people WDLA whose capacity for willed action remains intact. However, there is a need for evaluation of this legislation to assess whether it can help alleviate differences in assessments of capacity amongst professionals.

This study also suggested that the social structures in which healthcare professionals operate have the power to constrain participation of people WDLA in the decision-making process. Healthcare professionals, particularly in a hospital environment, perceived that they were under constant pressure to discharge patients, which increased

the risk of people WDLA being marginalised in the decision-making process and discouraged the involvement of advocates. In addition, the lack of time healthcare professionals had to spend with a client, particularly those with communication deficits, appeared to be a factor which limited opportunity of people WDLA to have their voices heard. Therefore, the cultural contexts of healthcare professionals and the social structures of their organisations are generative mechanisms which can constrain participation of people WDLA in the decision-making process.

Risk-averse society

People WDLA are reported to be at greater risk of harm than those living with others in the community (De Witt, Ploeg & Black 2010; Waugh, F 2009) and this may be a factor contributing to healthcare professionals' prioritisation of safety over agency. It appeared that this culture, for a minority of healthcare professionals, gave rise to a belief that people WDLA should be prevented from participating in any activity that involves an element of danger. This perspective removes all agentic power from people WDLA. However, the majority of healthcare professionals seemed to consider that people WDLA should be allowed to exert agentic power as long as there was no perceived risk associated with their choices or decisions. In circumstances where risk was perceived, these professionals were of the view that decision-making power should be removed from the person WDLA and that decisions should be made by others reflecting their best interest. Martin and Bartlett's (2003) work supported this finding, noting that when risks arose in a decision-making process many people with dementia had difficulty being heard. Therefore, it appears that healthcare professionals' perspectives on risk and their cultural contexts have a major impact on the level of agentic power afforded to people WDLA.

Consistent with findings on capacity, although the assessment of risk can have a profound effect on the agentic power of people WDLA, there is little guidance available to healthcare professionals on how assessments should be conducted (Manthorpe & Moriarty 2010). Research has also shown that there was wide variation in the understanding of risk among healthcare professionals (Clarke, CL et al. 2011). In addition, this study found that it was not clear what types of risks were to be considered and how ‘best interest’ was defined by healthcare professionals. Importantly, Clarke (2000) found that the construction of risk by healthcare professionals was not consistent with the construction of risk by people with dementia; healthcare professionals emphasised safety while people with dementia emphasised self-identity and interpersonal relationships. Similarly, this study found that the main focus for healthcare professionals was the physical domains of risk, while for people WDLA and their advocates it was the emotional domains of risk, such as loss of agency and autonomy. Evidence of differences in priority was even apparent from the number of times the words ‘risk’ and ‘safety’ were mentioned in focus groups and interviews conducted with healthcare professionals (risk =49 times, safety=10) compared to interviews conducted with advocates and participants WDLA (risk=2, safety=1). Although people WDLA were aware of physical risks involved in living alone, research has shown that they were not worried about them and were willing to accept them (Duane, Brasher & Koch 2013; Harris 2006); maintaining agency and living independently were of greater concern (Harris 2006). By focusing only on physical risks, healthcare professionals fail to consider the priorities for people WDLA and the emotional risks involved in losing agentic power. The need for further research to explore the emotional risks of disempowerment for people WDLA has previously been identified (Gilmour 2004). This study concurs and suggests further research is needed to explore the emotional risks involved in removing agentic power from people WDLA.

Manthorpe and Moriarty (2010) considered that one of the greatest barriers to people with dementia and their autonomy was the overly cautious approach to risk. In this study, healthcare professionals acknowledged that as society became more risk-averse and more litigious they became more cautious, resulting in greater temptation to admit people WDLA to institutional care, as it was viewed as a safe environment. This finding is consistent with other studies which have shown that people WDLA were placed in residential care facilities at disproportionately higher rates than those with similar levels of impairment residing with others (Ebly, Hogan & Rockwood 1999; Freedman 1996; Yaffe et al. 2002). The social and cultural contexts of healthcare can therefore diminish agentic power and constrain participation of people WDLA in the decision-making process. If risk is to be reframed researchers have identified the need to review social and cultural contexts and the extent to which physical risk is privileged for people with dementia (Clarke, CL et al. 2011). In addition, this study has shown that healthcare professionals may be more open to risk in circumstances where a substitute decision-maker exists, who can take responsibility for the consequences of the decision, or where there is a monitor in place to assess the person's safety. This approach may mitigate the concerns of healthcare professionals but it does disenfranchise people WDLA with no family support. There is the potential for advocates to expand their role and act as monitors for people WDLA, which could serve to alleviate some of the concerns of healthcare professionals. In building on Manthorpe and Moriarty's (2010) research, this study indicates that one of the greatest barriers to the autonomy *and* agentic power of people WDLA was healthcare professionals' overly cautious approach to risk, particularly for those with limited family support.

Much of the research on people WDLA has contributed to a culture of privileging safety over agency as studies have predominantly focused on the physical risks of living alone

with dementia (Ebly, Hogan & Rockwood 1999; Tierney, Charles, Jaglal, et al. 2001; Tierney et al. 2004; Tierney et al. 2007; Tuokko, MacCourt & Heath 1999). Few studies have included the perspectives of the person with dementia on risk or on mechanisms aimed at supporting them to manage such risks in their daily lives (Harris 2006; Manthorpe 2004). No specific studies were identified which addressed the emotional risks involved in losing agentic power or of being marginalised in the decision-making process. While living alone with dementia poses risks to the individual, a risk-averse social context is a mechanism which diminishes agentic power of people WDLA, and also has negative consequences. Therefore, a more nuanced assessment of risk may be required.

Trusting relationship with a proxy

In this study the majority of participants WDLA were aware that they were losing cognitive ability and had begun to experience difficulties in exerting power of agency. In recognising this difficulty some people WDLA were willing to ask for and accept the support of others and through this support they were able to retain some power of agency. Research has shown that the level of support a person with dementia was willing to accept depended upon how the support was offered; if offered in a subtle way, where people with dementia still felt in control of their own decisions, they were more likely to accept support (Fetherstonhaugh, Tarzia & Nay 2013). This study has established that the existence of a trusting relationship between the person WDLA and their proxy was critical to the acceptance of support. It appeared that the effectiveness of this relationship in facilitating power of agency depended on the participant WDLA trusting that the proxy would only act in accordance with their wishes, would get involved only upon request, and would not try to take over in the decision-making process. In addition the proxy had to trust that the person WDLA possessed power of agency and the capacity to make certain decisions. This trusting relationship is shown to be a generative mechanism which can act to facilitate power of agency of people WDLA.

Although this relationship can facilitate power of agency it involves an element of risk and requires people WDLA to overcome their fear of losing agency. Several participants WDLA feared that interacting with others might expedite their loss of agency, which in turn cultivated an environment of mistrust. Gilson (2003) reported that a trusting relationship can break down barriers that constrain cooperative behaviour but recognised that it was easier for those in a position of power to trust rather than those with fewer resources. In acknowledging the need for support, people WDLA must overcome their fear, and trust that they will not be judged by others as incapable of making their own decisions or incapable of remaining at home. If these elements exist, a trusting relationship can provide a mechanism to facilitate agency of people WDLA.

Although this mechanism has the power to facilitate agency, if abused it also has the power to remove it, as evidenced by the financial abuse of one participant WDLA by a family member. Within this relationship, the proxy has access to personal and financial information and can also have the power to influence the person WDLA or act without their knowledge. As discussed in Chapter Five, this abuse can often go undetected for considerable time, as little may be known about this relationship and the appropriateness of the proxy. Therefore, this trusting relationship is a mechanism which can facilitate or remove power of agency and the outcome is influenced by the actors involved.

In Australia, the importance of a trusting relationship for people WDLA is gaining in significance as there has been a major shift in healthcare policy towards providing greater flexibility and choice for consumers of aged care services (Australian Institute of Health & Welfare 2012). The benefit of a proxy is that he/she can help the person WDLA understand their options and support them in the selection process, thus ensuring the agency of people WDLA is facilitated. However, people WDLA who have no family and limited opportunity to establish a trusting relationship may be significantly disadvantaged

with this shift in healthcare policy and may struggle to exert power of agency. Therefore, an important consideration in maximising consumer participation of people WDLA is the presence of a trusting relationship. This trusting relationship has the potential to assist people WDLA to retain their power of agency for longer.

Features of advocacy that facilitate participation

Data from Chapter Five showed that independence, time and style of communication were important features of advocacy that assisted in building a trusting relationship between advocates and participants WDLA. Similar to a trusting relationship with a proxy, this relationship with an advocate is found to be a generative mechanism that enhanced the agency of participants WDLA. Within this trusting relationship, participants WDLA seemed comfortable to discuss concerns of potential abuse and through advocate support were able to exert power of agency. Some participants WDLA also found it easier to discuss their diagnosis with an independent person, with whom there was no emotional connection, rather than a family member. In addition, an independent relationship was shown to help safeguard against cultural and structural bias, protecting participants' agentic power and ensuring their wishes were kept to the forefront in the decision-making process.

This trusting relationship with the advocate was also shown to have the potential to influence the temporal orientations of agency. As previously discussed, fear over loss of agency was a source of anxiety for participants WDLA, which often led to a shift in temporal orientation to the past. Through this relationship and by helping participants' WDLA focus on their existing capabilities rather than on their losses, advocates initiated a reduction in anxiety and an increase in self-belief in their power of agency. This appeared to shift orientation from the past and move it towards the present and future, which encouraged participants WDLA to adopt strategies to cope with dementia and to

make plans for the future while they still had capacity. Therefore, a trusting relationship between the person WDLA and the advocate has the power to shift temporal orientations of agency towards the present and future, thus enhancing the power of agency of people WDLA.

This trusting relationship presents advocates with the power to exert influence over the actions and decisions taken by participants WDLA. It was suggested that positive influence, such as persuading participants WDLA to accept support services, enabled participants to remain living at home for longer. However, there was also a risk that advocates could exert too much influence, resulting in removal of agency from participants WDLA and in disregard of their wishes. Cantley, Steven and Smith (Cantley, Steven & Smith 2003) recommended that to minimise these risks advocacy organisations should have clear structures in place defining the boundaries. These structures could also help alleviate the variation in understandings of the term ‘influence’ amongst advocates highlighted in this study.

There was also concern that participants WDLA could become too dependent on this relationship and lose the ability to exert agency in the absence of the advocate. At the same time there was also a risk that the advocate could become too close to the person WDLA and lose objectivity, thus jeopardising their safety. Again, these issues highlight the importance of establishing boundaries through organisational procedures and appropriate advocate monitoring systems, which is consistent with the findings of another advocacy study by Cantley, Steven and Smith (2003). These systems would not only protect the person WDLA, they would also provide a level of protection for the advocate (Wells 2006). This trusting relationship with the advocates is a generative mechanism which, under the right conditions, has the power to enhance agentic power, power of agency and self-belief of participants WDLA and to shift their temporal orientations of

agency to the present and future. Organisational structures, through procedures and monitoring practices, have the ability to ensure that only the positive mechanisms of a trusting relationship are activated.

Although time is an important component in building a trusting relationship, time spent by advocates is also a generative mechanism of agency as it enhances the power of agency and self-belief of participants WDLA. Advocates invested considerable time with participants WDLA to gain an understanding of their needs, provide them with information and support them in the decision-making process. This time facilitated power of agency of participants WDLA. This time also afforded people WDLA with communication deficits, particularly those from a culturally and linguistically diverse background, the opportunity to express themselves. It also enabled advocates to develop a deeper understanding of the person WDLA, including their life history and an appreciation of how this might influence their decisions. A shared understanding of the person WDLA was demonstrated by consistency between the scores of advocates and their clients in the QOL-AD questionnaire.

Moreover, the study has shown that advocates spending time with participants WDLA increased their belief in their own power of agency. This was achieved through time invested in communicating with the participant WDLA to identify their concerns, to provide them with the relevant information, to work through the various options with them and to support them in exerting power of agency over their own decisions.

Margiotta et al. (2003) and Wright (2006) similarly found that through taking time to talk and listen to older people, their self-confidence and self-esteem increased. This finding is significant, as a review of the subjective needs of people with dementia found that there were a large number of needs in the domains of self-esteem for people with dementia (Van der Roest et al. 2007). Self-belief as previously discussed, is an essential component

that facilitates power of agency and, by increasing self-belief, the desire of the person WDLA to participate in the decision-making process may also increase. This increase in self-belief has the potential to reduce the effects of the stigmatisation of dementia. Therefore, spending time with participants WDLA is a mechanism which has the power to enhance power of agency and self-belief. In contrast, Independent Mental Capacity Advocates appointed in the United Kingdom under the *Mental Capacity Act 2005* are expected to spend an average of only eight hours with each client (Redley et al. 2009). Although the introduction of these advocates may increase opportunities for participation in the decision-making process, this study would suggest that the limited time allowed fails to maximise agency and the ability of people WDLA to participate in the decision-making process.

There is a risk in spending considerable time together that people WDLA and/or the advocates could become emotionally involved or come to view the relationship as a friendship. This could lead to difficulty in withdrawing from the relationship, particularly in circumstances where support is limited. This study has established that the advocacy organisation had not given due consideration to the withdrawal of this relationship or to its impact on the well-being of the person WDLA and the advocate. Cantley, Steven and Smith (2003) recommended that from the beginning, plans for intervention should include plans for the withdrawal of the service. This study concurs that it is essential that a plan for withdrawal from this relationship be in place to ensure that the agency and well-being of the person WDLA is maintained.

A further generative mechanism of advocacy that facilitates agency of participants WDLA is the positive cultural context of advocates. Advocates were of the opinion that the majority of participants WDLA had the ability to participate in the decision-making process and therefore perceived them as active agents. Their motto was '*helping you stay*

in control' and there was a shared belief amongst advocates that the more a person WDLA can achieve for themselves the better they feel. The cultural context of advocates strongly endorsed and protected the right of people WDLA to participate in the decision-making process. Advocates perceived their role was to support the person WDLA to express their wishes and to support them in the decision-making process. Therefore, the cultural contexts of advocates have the capability to enhance power of agency and agentic power of people WDLA. Although advocacy through these mechanisms can facilitate participation of people WDLA in the decision-making process, the study showed that there was a clear lack of understanding of advocacy and the advocate role among healthcare professionals and people WDLA. This lack of understanding is limiting the use of the advocacy service and its effectiveness in supporting people WDLA in the decision-making process. Yet the structural constraints of the advocacy service were limiting opportunities to increase knowledge and provide clarity on the advocate role across the community.

Power of people WDLA to participate in the decision-making process

Successful participation was reported to depend on individuals possessing agency and the ability to shape the actual processes that facilitate their involvement (Tritter & McCallum 2006). In order to explore the power of people WDLA to participate in the decision-making process it was therefore necessary to understand how dementia influenced a person's ability to exert action and its effect on their agentic power. Based on the findings from this study the following figure presents a diagrammatic representation of an agency model to maximise participation of people WDLA in the decision-making process.



Figure 6: Agency model to maximise the participation of people WDLA

This study showed that although dementia constrained power of agency, the majority of participants with mild to moderate dementia who lived alone had the ability to exert power of agency and participate in the decision-making process. The ability to exert agency relied upon a person's belief in their own power and was also influenced by the temporal orientations of agency and by the agentic power of people WDLA. Therefore, as shown in the diagram above this study would suggest that successful participation of people WDLA in the decision-making process depends upon four critical components of agency: power of agency; present and future orientations of agency; self-belief, and; agentic power.

Agentic power of people WDLA was shown to be constrained by healthcare professionals' perspectives on the decision-making capacity of people with dementia and the risk-averse society in which they operate. These social and cultural contexts limited the opportunity of participants WDLA to participate in the decision-making process. In contrast, three features

of advocacy were identified which significantly influenced the critical components of agency: time spent; positive cultural context, and; a trusting relationship. As depicted in the diagram above time spent with the person WDLA has the ability to positively influence two critical components of agency, which are self-belief and power of agency. The study suggests that a positive cultural context has also the ability to positively influence agentic power and power of agency while a trusting relationship with the person WDLA had the power to influence all four critical components of agency. These mechanisms, under the correct conditions, have the ability to move people WDLA from the lowest rungs of Arnstein's ladder of participation to varying degrees of citizen power (Arnstein 1969).

Conclusion

This study has established that loss of functional capacity attributed to dementia reduced power of agency and self-belief and narrowed the social world of participants WDLA.

Although, participants were losing power of agency they were at the same time exerting power of agency to employ strategies to cope with the impact of dementia. These strategies appeared to be aimed at either helping people WDLA cope with loss or at finding ways to maintain power of agency. The study indicated that the temporal orientations of agency influenced the power of agency of participants WDLA. A past orientation had the ability to enhance or constrain power of agency, while present and future orientations of agency had the ability to enhance it. Self-belief was also identified as a mechanism that could enhance power of agency, yet stigmatisation of dementia was shown to have the power to diminish self-belief.

Furthermore, the social structures and cultural contexts operating around people WDLA were shown to have the power to influence agentic power and their ability to participate in the decision-making process. Lack of a common understanding of decision-making capacity and divergent approaches to capacity assessments seemed to considerably

increase the risk of marginalisation of people WDLA from the decision-making process. Further a risk-averse society, leading to prioritisation of safety over agency, was also shown to influence the ability of people WDLA to participate in the decision-making process. In contrast, findings suggest that the presence of a trusting relationship with a proxy could help people WDLA maintain power of agency.

This study also identified three features of advocacy which, under the right circumstances, had the power to facilitate agency of people WDLA, these were: time spent with the person WDLA; a trusting relationship between the person WDLA and the advocate, and; the cultural context of advocates. These features had the ability to positively influence the critical components of agency and to maximise the participation of people WDLA in the decision-making process.

Chapter 7: Conclusion

Introduction

The aim of this study was to explore the power of people WDLA to participate in decision-making processes with advocacy support. This was achieved by examining how dementia affected agency of people WDLA and the factors that influenced their agentic action. Also examined in this thesis were the features of advocacy that facilitated participation of people WDLA in the decision-making process. This final chapter focuses on these findings and discusses how the findings related to the research aim.

Research conducted with people WDLA about their own experiences is very limited and this study contributes to the body of knowledge and shows that people WDLA with mild to moderate dementia can provide valuable information on the impact of dementia on their lives and their responses to it. A critical realist perspective provided a useful framework for understanding the mechanisms of the decision-making process as it helped to explore what worked for whom and why and the different ways in which interventions such as advocacy interacted with people WDLA and with settings to create varied outcomes.

This chapter begins by summarising the key findings and proceeds to the conclusions arising from the study. An evaluation of the study which presents the strengths and limitations then follows, and the chapter concludes with a discussion of directions for further research.

Key findings of the Study

The previous three chapters have presented the findings and theorised on mechanisms underpinning agency and participation of people WDLA in the decision-making process. A summary of these key findings, answering the three research questions, is provided below.

How does dementia impact on the agency of people WDLA?

Dementia led to a loss in functional capacity and this loss had a significant impact on the power of agency of people WDLA, as their choices and control over their lives were diminished and their reliance on others was increased. Loss of power of agency reduced the ability of people WDLA to participate in self-affirming and meaningful activities, resulting in decreased self-esteem and loss of identity. These factors combined were found to increase the risk of social isolation of participants WDLA. Although, participants were losing power of agency, the majority of them were at the same time exerting power of agency in order to adopt strategies to cope with the effects of dementia. The home was identified as an environment which helped protect and maintain power of agency of people WDLA. This study also indicated that present and future orientations of agency were mechanisms which could influence and enhance power of agency. Yet people WDLA appeared reluctant to shift orientation towards the future due to fears associated with their inevitable future decline. Self-belief was shown to be a critical component of agency, and a mechanism which could help shift orientation to the present, but this study showed that self-belief was often diminished as a consequence of the stigmatisation of dementia. Therefore the cultural contexts of people WDLA and the extent of power perceived by them to take action can affect their emotional well-being.

What are the factors influencing agentic action of people WDLA?

This study identified three factors which influenced agentic action of people WDLA, namely: power of others to influence decision-making capacity; a risk-averse society, and; a trusting relationship with a proxy. Cultural contexts were shown to influence decision-making capacity assessments of people WDLA. These contexts often differed between and among healthcare professionals and advocates, leading to differences in assessment outcomes.

This study found that for the majority of healthcare professionals, safety of people WDLA was prioritised over agency and this culture was responsible for constraining agentic power of people WDLA. The social structures in which healthcare professionals operate also appeared to be responsible for limiting the opportunity of people WDLA to have their voice heard, thus reducing their ability to participate in the decision-making process.

Further, it was indicated that a risk-averse society influenced healthcare professionals' assessments of risk and led to greater emphasis on the physical domains of risk while ignoring emotional risks associated with loss of agentic power. This social context was found to contribute to a greater temptation to admit people WDLA to a residential care facility, viewed as a safe environment.

In contrast, a trusting relationship between a person WDLA and a proxy was shown to be a mechanism that had the potential to enhance power of agency of people WDLA. Through the support of this relationship, people WDLA were able to maintain control over certain aspects of their lives for longer. However, establishing this trusting relationship involved an element of risk, as this relationship, if abused, could diminish agentic power of people WDLA.

What are the features of advocacy that facilitate participation of people WDLA in the decision-making process?

This study identified three mechanisms of advocacy, which, under the correct conditions, have the power to facilitate participation of people WDLA in the decision-making process. These were: a trusting relationship between the person WDLA and the advocate; time spent with the person WDLA, and; the cultural context of advocates. This trusting relationship was shown to have the power to facilitate and influence the four key components of agency, which are: agentic power, power of agency, self-belief, and temporal orientations of agency. Independence, time and style of communication were found to be important features of advocacy that assisted in building this relationship.

The study also suggested that through spending time with the person WDLA their self-belief and power of agency could be enhanced. In addition, advocates appeared to perceive that the majority of people WDLA were active agents and viewed their role as protecting the right of people WDLA to participate in decision-making processes. This positive cultural context had the ability to enhance power of agency and agentic power of people WDLA.

Although these mechanisms facilitated participation of people WDLA in the decision-making process, the effectiveness of advocacy and future success of the service appeared to be contingent upon: early referrals; clear procedures and mentoring supports for advocates; common understanding of dementia advocacy and the advocate role; clear differentiation of roles between advocates and other healthcare professionals, and; a common understanding of capacity and risk for people WDLA.

Conclusions arising from the study

This research made a number of contributions and provided evidence on how agency of people WDLA was affected following a diagnosis of dementia, which was essential in

understanding participation of people WDLA in the decision-making process. The study showed that for the majority of participants WDLA their power to participate had been diminished due to a loss in power of agency, agentic power and self-belief, and an inability to shift temporal orientation to the present and future. However, external factors provided by others, such a positive cultural context, time spent with the person WDLA and a trusting relationship, were shown to have the ability to enhance and influence these critical components of agency. Therefore, the study suggests that there is the potential to increase participation of people WDLA in the decision-making process through mechanisms aimed at maximising these four critical components of agency.

These findings contribute to knowledge about people WDLA and provide an explanatory theory from which others can test the theoretical premises on a larger population. These findings have implications for policy makers, healthcare professionals, advocates and carers of people WDLA. Based on these findings the following recommendations, which provide suggestions on how to enhance participation of people WDLA in the decision-making process, are made:

Recommendation 1: There is insufficient understanding of the importance of agency for people WDLA and its effect on their behaviours and ability to adapt to dementia. It is recommended that an educational program be developed for healthcare professionals and carers in which attention be given to the ways in which their role can positively influence the critical components of agency of people WDLA.

Recommendation 2: Policy makers should focus on increasing understanding of the variability in decision-making capacity of people with dementia and should work towards developing a universal capacity assessment tool which could help to minimise variation in capacity assessments.

Recommendation 3: Healthcare professionals should review how their cultural contexts are prioritising safety over agency and influencing the ability of people WDLA to participate in the decision-making process. These professionals should consider the benefits of involving an independent person in a trusted relationship with the person WDLA in the decision-making forum.

Recommendation 4: Further research should be conducted on the development of a risk assessment/enablement tool which considers various factors that can influence risk, such as stage of dementia, level of informal support, and the life history of the person WDLA. In addition, this research should also explore ways to assess and balance the safety of, and emotional consequences for, people WDLA as part of this assessment.

Recommendation 5: Policy makers should provide greater clarity on the current and future expectations of dementia advocacy and their role in the decision-making process. Advocates should consolidate this space and invest in promoting and increasing understanding of the service among potential service users and healthcare professionals.

Recommendation 6: Dementia advocacy being in its infancy, best practice should be shared across organisations to facilitate the establishment of detailed training programs, standard operating procedures and mentoring practices to support advocates. In addition, the National Disability Advocacy Program quality assurance system should be expanded to include dementia advocacy and the unique complexities associated with fluctuating capacity.

Evaluation of the Study

This section discusses the strengths and limitations of the research approach and the implications for further research.

Strengths of the research approach

The findings from this qualitative study were drawn from nine people WDLA, four advocates and twenty-one healthcare professionals. The use of multiple data sources enabled the researcher to obtain an in-depth understanding of the decision-making process and the numerous factors which influenced participation of people WDLA. The triangulation of data from multiple sources and multiple methods strengthened the validity of the findings and enabled the researcher to assess the consistency of responses from people WDLA. The use of a qualitative research design also provided the opportunity to clarify responses and restructure questions, which facilitated the involvement of people WDLA in research.

Critical realism, using a process of abduction and retroduction as a guide, allowed the thesis to develop explanatory theories of agency and to expand on knowledge of people WDLA in the decision-making process beyond the empirical domains of reality. By taking this approach the study provided valuable insight into the factors that can facilitate or inhibit participation of people WDLA in the decision-making process.

Limitations of the research approach

Although this study contributed to knowledge on participation of people WDLA in the decision-making process, it does have limitations. Clinical evaluations of participants WDLA were not conducted and the study relied on the Global Deterioration Scale rated by the advocate for each client. Therefore, it is not possible to confirm the person's diagnosis, though all of the participants WDLA had been referred to the dementia advocacy service by healthcare professionals. The sample of participants WDLA was also drawn from those with a GDS Stage 4 or lower on the assumption that they would be able to recall using advocacy services. However, not all participants were able to recall their specific advocacy experiences. In addition, those with a GDS Stage 4 or lower who could

recall their advocacy experiences may not be reflective of the experiences of people WDLA with a GDS Stage 5 or higher.

Furthermore, the reflections and experiences were all drawn from service users, advocates and healthcare professionals associated with the same advocacy organisation. It is possible that the experiences of people WDLA in this study may not be representative of the greater population and that the views of participants on advocacy in facilitating participation may differ across advocacy organisations. In addition, because this study sampled only people WDLA who had used an advocacy service, their perspectives may be more positive towards advocacy services may differ to those who have not used an advocacy service. Having experienced the benefits of advocacy service they may be more positive about the need for advocacy than individuals with similar conditions who have not accessed advocacy services. Future studies could investigate decision making in people WDLA who have not had access to advocacy services. The sample size of people WDLA was also small, which means the results are not generalizable.

Additionally, as a critical realist study, findings are always considered fallible because reality is stratified and interpretations are mediated by pre-existing conceptual resources. However, the use of an established process to analyse the data ensured that although the findings cannot be deemed the objective truth, they are robust.

A further limitation arose from the use of the same name for all advocates as this prevented the researcher from addressing some disparity between advocates, but the need to protect advocate confidentiality was considered to be more important, particularly given the sensitive nature of the information provided.

Directions for further research

This study showed that people with mild to moderate dementia who live alone have the ability to participate in research and are willing participants. yet they remain an under-researched group. One of the reasons for this may lie with the emphasis being on capacity to consent, which is reflected in the literature on people with dementia. In attempts to protect researcher participants, ethics committees often require consent to be obtained from, or verified by, a family member, which diminishes the opportunity of people WDLA with no family to participate in research. Methods and tools to verify capacity to consent can act as a deterrent, therefore, as an alternative approach, this study highlights how a shift of emphasis to the researcher, assessing their skills in communicating with people with dementia and ability to understand non-verbal signs, could be preferable. If deemed adequate, the researcher could assess capacity to consent and obtain consent through non-stressful discussion with the person WDLA. This approach has the potential to increase participation of people WDLA in research and thereby to ensure that their views are heard. The appropriateness of this shift in emphasis to the researcher in assessing consent requires further investigation.

The current political and legislative focus on increasing consumer participation and providing greater flexibility and choice for consumers cannot succeed for people WDLA unless there are systems in place to facilitate the critical components of agency. To effectively address these issues it will be necessary to acknowledge the sociocultural contexts which have the power to influence the level of participation. Further research is needed to explore the ways in which the critical components of the agentic process can be enabled if participation of people WDLA in the decision-making process is to become a reality. This research should also evaluate the emotional risks of disempowerment and the effects on the health and well-being of the person WDLA.

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Appendix 2a: Person WDLA Consent Form

1. I have read and understood the “Information Sheet” for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves completing a questionnaire and being interviewed for approximately one hour. I understand that the interview will be audio-taped.
4. I understand that the interview process may carry a risk of discomfort but I also understand that I do not have to answer any specific questions and that I can stop the interview at any time.
5. I have been informed that the results of this research may not be of any direct benefit to my support needs.
6. I understand that all research data will be securely stored on the University of Tasmania premises for five years following publication and will then be destroyed.
7. Any questions I have asked have been answered to my satisfaction.
8. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
9. I understand that the researchers will keep my identity confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
10. I agree to participate in this research. I understand that I may withdraw at any time and this will not affect my future access to care or services and, if I so wish may request that any data I have supplied up until 1st February 2012 be withdrawn from the research.

Name of Participant

SignatureDate.....

Name of Witness.....

SignatureDate.....

Statement by Researcher

☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Researcher has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Researcher.....

SignatureDate.....

Appendix 2b: Advocate Consent Form

1. I have read and understood the 'Information Sheet' for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves completing a QOL-questionnaire for each person living alone with dementia recruited to the study and to being interviewed for approximately 1 hour. I understand that the interview will be audio-taped. I understand that the information to be collected will involve:
 - Answering questions about my experiences of being an advocate to people living alone with dementia.
 - Discussing the advocacy model and the services provided.
 - Discussing barriers and enablers to the service.
 - Providing suggestions for improving the advocacy services.
4. I understand that this study has no particular risks for me, but any interview process may potentially evoke uncomfortable feelings. If this does happen the interviewer will give you the opportunity to stop discussing that topic and also to consider stopping the interview completely.
5. I understand that all research data will be securely stored on the University of Tasmania premises for five years following publication and will then be destroyed.
6. Any questions that I have asked have been answered to my satisfaction.
7. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
8. I understand that the researchers will keep my identity confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
9. I agree to participate in this investigation. I understand that I may withdraw at any time without any effect and, if I so wish may request that any data I have supplied up until the 1st February 2012 be withdrawn from the research.

Name of Participant.....

SignatureDate.....

Statement by Researcher

☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Researcher has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Researcher.....

SignatureDate.....

Appendix 2c: Healthcare Professional Consent Form

1. I have read and understood the 'Information Sheet' for this project.
2. The nature of the interview/focus group and possible effects has been explained to me.
3. I understand that I have been asked to participate in a 1.5 hour interview/focus group about the usefulness of advocacy for a person living alone with dementia. I understand that the interview will be audio-taped. I understand that the information to be collected will involve:
 - Answering questions about my experiences of assessing the needs of people living alone with dementia and referring them to the advocacy service.
 - Discussing how beneficial I believe advocacy is to the person living alone with dementia and to the health service provider.
 - Discussing when is the ideal time and circumstance to involve the advocate.
 - Providing suggestions on best practice for collaborations between the health service provider and the advocate.
4. I understand that participation involves no particular risk. I understand that the confidentiality of information disclosed in the focus group setting relies on the discretion of other participants and so cannot be guaranteed.
5. I understand that all research data will be securely stored on the University of Tasmania premises for five years following publication and will then be destroyed.
6. Any questions that I have asked have been answered to my satisfaction.
7. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
8. I understand that the researchers will keep my identity confidential and that any information I supply to the researcher will be used only for the purposes of the research.
9. I agree to participate in this investigation. I understand that I may withdraw at any time without any effect and, if I so wish may request that any data I have supplied up until the 1st May 2012 be withdrawn from the research.

Name of Participant

SignatureDate.....

Statement by Researcher

☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Researcher has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Researcher.....

SignatureDate.....

Appendix 3a: Information Sheet for People WDLA

Invitation

You are invited, on behalf of the Wicking Dementia Research & Education Centre, to participate in a research study on the exploration of the essential features of an effective advocacy model that facilitates and supports the decision-making capacity of those living alone with dementia.

The study is being conducted by the following individuals:

Dr. Christine Stirling
Dr. Emily Hansen
Corinna Dwan

Senior Research Fellow
Lecturer in Sociology
PhD candidate

1. 'What is the purpose of this study?'

This study seeks to examine the role that advocates play in the life of a person living alone with dementia. It aims to understand what are the major decisions the person faces and how do these decisions affect their lives. This study hopes to give people the opportunity to describe the role advocates played in these decisions and to understand how advocates can help in retaining autonomy for the decisions of a person living alone with dementia.

2. 'Why have I been invited to participate in this study?'

We would like to ask you to participate in this Advocacy Model Project because you have used the advocacy service in the last six months and your experiences will help us understand how the advocacy service can assist people in their decision-making process and help them to remain independent.

3. 'What does this study involve?'

If you agree to participate you will be asked to complete a brief quality of life questionnaire and to be interviewed on one or two occasions for about 1 hour each time. The interview will involve talking about the important decisions for you and the role the advocate has played in the decision-making process. With your agreement the interview will be audio-taped and then transcribed. The interview can take place in your home or in any other mutually agreed location.

The interviewer will be Corinna Dwan who can be contacted on ph xxxxxx

4. 'Are there any possible risks from participation in this study?'

Although we will do our best to deal with all matters sensitively and in confidence, it is possible that talking about your experiences will cause some emotional distress. If this does happen the interviewer will give you the opportunity to stop discussing that topic and also to consider stopping the interview completely. Professional assistance may be provided to any participant who experiences emotional distress as a result of the interview process.

5. 'Are there any possible benefits from participation in this study?'

There may be no direct benefit for you. However, it is hoped your feedback will improve the advocacy service provided to people living alone with dementia.

6. ‘Will it be confidential?’

The information you provide will be kept confidential by us and only authorised researchers will know your name or any other identifying information. We will use a pseudonym to record your contribution and will also change any details that could be used to identify you. Your contact details will be kept in a locked filing cabinet separate from the interview material. Audio-tapes will be digitally stored on a password secured server hard drive. All data will be destroyed or deleted after a period of five years has elapsed since publication.

7. ‘Do I have to participate?’

Participation in this research is voluntary. There will be no consequences to you or to the care and services that you receive if you do not want to participate in this study.

You can choose to stop the interview at any time without giving a reason. You can also refuse to answer any specific questions. If you choose to withdraw from the project, you may also choose to withdraw the information you have provided up until the 1st February 2012. Following this date, the information will be coded and analysed, and withdrawal of the data will not be possible.

All information you provide will be treated in a confidential manner, and your name will not be used in any publication arising out of the research.

8. ‘What if I have questions about this research?’

If you would like to discuss any aspect of this study please feel free to contact either Corinna Dwan on ph xxxxxx or Dr. Christine Stirling on ph xxxxxx. Either of us would be happy to discuss any aspect of the research with you.

This study has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on ph xxxxxxxx or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote the ethics reference number H0011667.

9. ‘Can I find out about the results of the research?’

A summary of the results of this project when completed will be sent to you. Please let the interviewer know if you would also like to receive a copy of your completed Quality of Life Questionnaire and we will arrange for this to be sent to you.

Thank you for taking the time to consider this study.

Please keep a copy of this sheet and the accompanying Statement of Informed Consent.

Appendix 3b: Information Sheet for Advocates

Invitation

You are invited, on behalf of the Wicking Dementia Research & Education Centre, to participate in a research study on the exploration of the essential features of an effective advocacy model that facilitates and supports the decision-making capacity of those living alone with dementia.

The study is being conducted by the following individuals:

Dr. Christine Stirling
Dr. Emily Hansen
Corinna Dwan

Senior Research Fellow
Lecturer in Sociology
PhD candidate

1. ‘What is the purpose of this study?’

The purpose of this research is to:

- Understand what are the major decisions the person living alone with dementia faces and how do these decisions impact on their lives?
- How can the advocacy model facilitate and support these decisions?
- Understand what are the barriers and enablers to effective advocacy.

2. ‘Why have I been invited to participate in this study?’

You have been asked to participate in the Advocacy Model project as you are an advocate to a person living alone with dementia.

3. ‘What does this study involve?’

You will be asked to complete a brief Quality of Life questionnaire for each of the recruited individuals living alone with dementia and agree to an interview conducted in a mutually agreed location. The interview will last for a maximum of one hour and will involve questions regarding how and under what circumstances advocacy services are provided and how capacity of the individual is assessed.

All interviews will be audio-taped. The information you provide will be kept confidential and only authorised researchers will know your name or any other identifying information. The information will only be made publicly available in a form that does not identify you.

4. ‘Will it be confidential?’

The information you provide will be kept confidential by us and only authorised researchers will know your name or any other identifying information. All paper records will be secured in locked storage and destroyed after a period of five years has elapsed since publication. Audio-tapes will be digitally stored on a password secured server hard drive. All data will be destroyed or deleted after a period of five years has elapsed since publication.

5. ‘Do I have to participate?’

Participation in this research is voluntary. While we would be pleased to have you participate, we respect your right to decline. You should not feel obliged to participate in any aspect of it. There will be no consequences to you if you decide not to participate. If

you decide to discontinue participation at any time, you may do so without providing an explanation. If you choose to withdraw from the project, you may also choose to withdraw the information you have provided up until the 1st February 2012. Following this date, the information will be coded and analysed, and withdrawal of the data will not be possible.

All information provided will be treated in a confidential manner, and your name will not be used in any publication arising out of the research.

6. ‘Are there any possible benefits from participation in this study?’

There is no payment made for joining this study and we cannot guarantee you will receive any benefits from this research. We hope that this research will contribute to the greater knowledge, insight and understanding of the role of advocacy in supporting people living alone with dementia in decision-making and assisting advocates in targeting their services towards the needs of the person.

7. ‘Are there any possible risks from participation in this study?’

The study has no particular risks for you, but any interview process may potentially evoke uncomfortable feelings.

8. ‘What if I have questions about this research?’

If you would like to discuss any aspect of this study please feel free to contact either Corinna Dwan on ph xxxxxxxx or Dr. Christine Stirling on ph xxxxxxxx. Either of us would be happy to discuss any aspect of the research with you. Once we have analysed the information we will be mailing / emailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study.

This study has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on ph xxxxxxxx or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote the ethics reference number H0011667.

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.

Appendix 3c: Information Sheet for Healthcare Professionals

Invitation

You are invited, on behalf of the Wicking Dementia Research & Education Centre, to participate in a research study on the exploration of the essential features of an effective advocacy model that facilitates and supports the decision-making capacity of those living alone with dementia.

The study is being conducted by the following individuals:

Dr. Christine Stirling
Dr. Emily Hansen
Corinna Dwan

Senior Research Fellow
Lecturer in Sociology
PhD candidate under the supervision of Dr
Christine Stirling and Dr Emily Hansen

1. 'What is the purpose of this study?'

Currently one-third of persons living with dementia live alone in the community and this number is expected to increase in the coming years. From the literature it is thought that this group of individuals is more at risk of being excluded from the decision-making process surrounding their own needs. In Tasmania over the past 10 years advocacy services have been available to support and facilitate a person living alone with dementia in the decisions they face. However, very little research on the advocacy model has been conducted as the work of advocates with people with dementia has only recently been seen as both possible and desirable in enabling people with dementia to retain autonomy. This project would like to address this gap.

This project aims to explore what are the essential features of an effective advocacy model and how can the advocacy model facilitate and support the decision-making of people living alone with dementia.

The purpose of this research is to:

- Understand what are the major decisions the person living alone with dementia faces and how do these decisions impact on their lives?
- How the advocacy model can facilitate and support these decisions?
- Understand what the barriers and enablers to effective advocacy are.
- Understand the views of the health service professionals and explore in what situations they would consider advocacy to be beneficial.

2. 'Why have I been invited to participate in this study?'

We would like to ask you to participate in this Advocacy Model Project because you are involved in the care and assessment needs of people who live alone with dementia and are often responsible for referring these individuals to the advocacy service.

3. 'What does this study involve?'

This research involves 4 focus groups of 5 individuals in each group. Each group will discuss the usefulness of advocacy for people living alone with dementia and the benefits for both the individual and the health service. It will discuss the type of circumstances and

ideal timing for a referral to the advocacy service. The focus group meeting is expected to take 1.5 hours.

The focus group discussions will be tape recorded and transcribed later. The focus group will be conducted in a place that is most convenient to the majority of participants.

If you indicate you wish to participate in a focus group discussion, please contact the Corinna Dwan on ph xxxxxxxx whereby instructions for the time and location will be provided to you.

4. ‘Will it be confidential?’

It is important that you realise that in participating in a focus group, your comments will be known to all other members of the focus group. Therefore, there is a risk that your comments may become known to others outside the group. Because of this risk it is essential that all members of the focus group ensure that any comments made “in confidence” by any member of the group remain confidential by not discussing what was said with anyone outside of the group. The information you provide will be kept confidential by us and only authorised researchers will know your name or any other identifying information. All paper records will be secured in locked storage and destroyed after a period of five years has elapsed since publication. Audio-tapes will be digitally stored on a password secured server hard drive. All data will be destroyed or deleted after a period of five years has elapsed since publication.

5. ‘Do I have to participate?’

Participation in this research is voluntary. While we would be pleased to have you participate, we respect your right to decline. There will be no consequences to you if you decide not to participate. If you decide to discontinue participation at any time, you may do so without providing an explanation. If you choose to withdraw from the project, you may also choose to withdraw the information you have provided up until the 1st May 2012. Following this date, the information will be coded and analysed, and withdrawal of the data will not be possible.

All information provided will be treated in a confidential manner, and your name will not be used in any publication arising out of the research.

6. ‘Are there any possible benefits from participation in this study?’

There is no payment made for joining this study and we cannot guarantee you will receive any benefits from this research. We hope though that this research will contribute to the greater knowledge, insight and understanding of the role of advocacy in supporting people living alone with dementia in decision-making and assist advocates in targeting their services towards the needs of the individual.

7. ‘Are there any possible risks from participation in this study?’

The study has no particular risks for you. If confidentiality is not adhered to by all participants of the focus group, there is a slight risk that your comments may become known to others outside the group.

8. ‘What if I have questions about this research?’

If you would like to discuss any aspect of this study please feel free to contact either Corinna Dwan on ph xxxxxxxx or Dr. Christine Stirling on ph xxxxxxxx. Either of us would be happy to discuss any aspect of the research with you. Once we have analysed the information we will be mailing / emailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study.

This study has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on ph xxxxxxxx or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote the ethics reference number H0011667.

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.

Appendix 4a: Interview guide for People WDLA

General Introduction

- I would like to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent. When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area. If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.
- How do you feel about the assessment you have undertaken? (Prompt: Did you find it difficult? Would you like it to deal with any other aspects of your life?)
- Can you share with me how you feel about dementia? (Prompt: When were you diagnosed? How does dementia affect your life at the moment? What do you understand by dementia?)

Decision-making

- Can you share with me what are the most important decisions for you in your life at the moment or over the last couple of years?
- Can you explain how these decisions make you feel (prompt: do you worry, how important is it that you are involved, how important is it that your wishes are respected?)
- Can you tell me what happens when you have a big decision to make in your life (Prompt: Who is involved? Who has the most influence?)
- Can you tell me about help you receive from family, friends or services and are you responsible for deciding what help you would like? (Prompt: Can you tell me if you are responsible for the everyday decisions about your life?, what to eat?, what to buy etc?. what doctor you go to? – How did you tell them what help you needed? How do you feel about their help?)

Advocacy questions

- Can you tell me how you became involved with the advocacy service? (Prompt: how was this service introduced to you?)
- Can you tell me about your interaction with the advocate? (Prompt: How long has the advocate been visiting you, Do you like the advocate calling to you?)
- Can you share your experiences of using the advocacy service? (Prompt: How did they help you? what decisions needed to be made? What role did the advocate take?)

- Can you tell me how you feel about the advocacy service?
- Under what circumstances do you think a person should have an advocate?
(Prompt: Do you think advocacy is needed? What type of decisions do you think advocates should be involved in? Do you think advocacy should be available to everyone?)
- Would you like the advocate service to do anything else? (Prompt: are there any improvements to the service you would like to see?)

Appendix 4b: Interview guide for Advocates

The What, Why, How, Who & When of Advocacy

- Can you tell me about your life story explaining why you decided to become an advocate? (leave to the end and ask if there's time)
- Can you describe to me in your own words “what is advocacy and your role as an advocate?”
- Can you tell me about the advocacy model you use? (How does your service operate)
- Can you explain the referral process of your clients to the advocacy service? (Prompt: Who refers them, why are they being referred – is a certain decision pending)
- Can tell me what you think are the ideal circumstances for advocate involvement (prompts: What is the ideal timing to involve an advocate and what decisions should involve advocacy, what individuals should be referred?)

Issues related to individual living alone with dementia

- Can you tell me what you see as the benefits of the advocacy service for the person living alone with dementia?
- Can you tell me generally about your interactions with your clients? (Prompt: How long does it take to build up a relationship? What the proportion is of instructed versus non-instructed clients?)
- Can you explain how you assess the consent to involvement by the person living alone? (prompt: what are your thoughts on providing advocacy to persons who are unable to instruct, how to you know they are happy with your involvement?)
- Can you explain how you assess the decisional capacity of the clients?
- Have you experienced difficulties with client communication and if so how do you deal with these problems?
- In situations where the client has moderate to severe dementia, how do you establish the wishes of the client and how do judge whether you are acting in the best interest of the person? (prompt: What is the non-instructed approach you use)
- What do you do in situations where you disagree with the wishes of the individual?

Advocacy Organisation

- What do you think are the characteristics and skills needed to be a good advocate? (Prompt: How do you become a qualified advocate? What training is needed and how is competency assessed? Do you have interactions with other advocacy organisations)
- Can you tell me is there a standard advocacy model available for all individuals and is this a universal model? (Prompt: Do you feel providing advocacy to a person with dementia is similar to advocacy in other areas? Can you tell me your thoughts on citizen/volunteer advocacy)
- Can you tell me about your relationships with Medical professionals and the service assessors and providers in your role as an advocate?
- Can you tell me about some of the current barriers to effective advocacy and are there ways which you see we could improve these issues?
- Tell me about what currently works really well with the service and if you could change anything in the service what would it be?
- Can you tell me about the differences between case workers and advocates?
- Can you tell me about the socio economic background of the majority of your clients? Is there a trend?

Appendix 4c: Interview guide for Healthcare Professionals

The following questions will be discussed by each of the focus groups and healthcare professional interviews

- ***Does advocacy facilitate the inclusion of individuals (living alone with dementia) in decisions about their own life and help individuals remain independent?***

Moderator to probe:

- What do they understand by the term advocacy?
- Is there a need for advocacy?
- What is their experience of advocacy?
- What are the benefits for the individuals?
- What are the benefits to Services?
- Does having access to an advocate improve the quality of life of an individual?

- ***What are the circumstances for referring a client to the advocacy service***

Moderator to probe:

- Why and when should an advocate be involved? (prompt: issued based or long-term establishing a relationship etc)
- Who should refer?
- At what stage of dementia when advocates are involved? (prompt: Does involving advocates early in the process have advantages or disadvantages?)
- Should it be compulsory to offer advocacy to individuals?

- ***What do you think are some of the challenges for effective advocacy?***

Moderator to probe:

- Under what circumstances does advocacy work well?
- Discuss some of the barriers and how could these be improved
- What is the relationship between the Service Providers and the advocates?

Appendix 5a: QOL Questionnaire for the Person WDLA

Quality of Life: AD (Questionnaire Version for the person living alone with dementia)				
The Researcher will administer this questionnaire.				
Circle responses				
1. Physical health	Poor	Fair	Good	Excellent
2. Energy	Poor	Fair	Good	Excellent
3. Mood	Poor	Fair	Good	Excellent
4. Living situation	Poor	Fair	Good	Excellent
5. Memory	Poor	Fair	Good	Excellent
6. Family	Poor	Fair	Good	Excellent
7. Closest relationship	Poor	Fair	Good	Excellent
8. Friends	Poor	Fair	Good	Excellent
9. Self as a whole	Poor	Fair	Good	Excellent
10. Ability to do chores around the house	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money	Poor	Fair	Good	Excellent
13. Life as a whole	Poor	Fair	Good	Excellent

Comments:

.....

Name of Participant

Name of Researcher.....

SignatureDate.....

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Appendix 5b: QOL Questionnaire for the Advocate

Quality of Life: AD (Questionnaire Version for the advocate)				
<i>The following questions are about your client's quality of life.</i> When you think about your client's life, there are different aspects, some of which are listed below. Please think about each item, and rate your client's current quality of life in each area using one of four words: poor, fair, good, or excellent . Please rate these items based on your client's life at the present time or within the past few weeks. Please circle your responses				
1. Physical health	Poor	Fair	Good	Excellent
2. Energy	Poor	Fair	Good	Excellent
3. Mood	Poor	Fair	Good	Excellent
4. Living situation	Poor	Fair	Good	Excellent
5. Memory	Poor	Fair	Good	Excellent
6. Family	Poor	Fair	Good	Excellent
7. Closest relationship	Poor	Fair	Good	Excellent
8. Friends	Poor	Fair	Good	Excellent
9. Self as a whole	Poor	Fair	Good	Excellent
10. Ability to do chores around the house	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money	Poor	Fair	Good	Excellent
13. Life as a whole	Poor	Fair	Good	Excellent

Comments:

.....

Name of Participant

Name of Advocate.....

SignatureDate.....

Name of Researcher.....

SignatureDate.....

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Appendix 6: Capacity to Consent Assessment Tool

Brief Assessment of Capacity to Consent based on UBACC	
1. What is the purpose of the study described to you?	
Response (2=to understand decisions you make, how these decisions impact you, how advocates can help)	Score
	0
	1
2	
2. Do you have to be in this study if you do not want to be?	
Response (2=No)	Score
	0
	1
2	
3. If you do participate in the study, what will you have to do?	
Response (2=complete questionnaire, agree to be interviewed talking or answering questions about important decisions and advocacy)	Score
	0
	1
2	
4. What do you do if you do not want to continue in the study	
Response (2=ask to stop)	Score
	0
	1
2	
5. What do you do if you are feeling uncomfortable?	
Response (2=say something, ask to stop interview)	Score
	0
	1
2	
6. Is there any possible risks to you in this study	
Response (2=possible discomfort or distress)	Score
	0
	1
2	
7. Is it possible that being in this study will not have any benefit for you?	
Response (2= yes)	Score
	0
	1
2	

Name of Participant

ScoreDate.....

Name of Researcher.....

Signature.....Date.....

Appendix 7: Invitation Letter

Wicking Dementia Research and Education Centre,
Menzies Research Institute,
University of Tasmania,
Private Bag 121,
Hobart 7000

Date:

Dear Sir/ Madam,

The Wicking Dementia Research and Education Centre are currently conducting a study looking at the role of advocacy in supporting and facilitating the decision-making process of people living alone with dementia. For further information on this study please refer to the Information Sheet enclosed.

As part of this study we want to establish 4 focus groups which will be composed of those individuals directly involved in providing care and assessing the needs and decision capacity of people living alone with dementia. The groups will be separated into the following categories:

- Geriatricians & Medical Practitioners
- Community Nurses
- ACAT Assessors
- Allied Health Professionals

The purpose of each focus group is to gain an understanding on the views of the health service professionals towards the advocacy service and to explore what situations they would consider advocacy beneficial. Also, best practice for collaboration between the health service provider and the advocate will be explored.

We would greatly appreciate your involvement in the study as your experiences and expertise in this area would be invaluable to the outcome. Involvement in this focus group consists of partaking in a one 1.5 hour long meeting.

If you are interested in participating or require any further information can you please contact either the Chief Investigator of the study:

Dr Christine Stirling

Ph: xxxxxxxx

or

Corinna Dwan

Ph: xxxxxxxx

Thanking you most sincerely for taking the time to consider your involvement.
Kind regards,

Dr Christine Stirling

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